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FINAL REPORT  
OF THE  
PALLIATIVE CARE TASK FORCE  
HAMILTON-WENTWORTH DISTRICT HEALTH COUNCIL

NOVEMBER, 1983



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FINAL REPORT  
OF THE  
PALLIATIVE CARE TASK FORCE  
HAMILTON-WENTWORTH DISTRICT HEALTH COUNCIL

NOVEMBER, 1983





# Hamilton-Wentworth District Health Council

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June 20, 1983

Mr. David Goldberg, Q.C., Chairman  
Hamilton-Wentworth District Health Council  
P.O. Box 2085, M.P.O.  
HAMILTON, Ontario  
L8N 3R5

Dear David,

I am pleased to present the Final Report of the Palliative Care Task Force. It is the sincere hope of the Task Force that Palliative Care services for the Hamilton-Wentworth Region will be improved and enhanced as a result of this report.

The Task Force would like to thank the various members of the community who participated in the development of our inventory. We would also like to thank Dr. Dorothy Ley, Executive Director of the Palliative Care Foundation and Dr. John Scott, consultant to the Ministry of Health on Palliative Care, who by their constructive criticism helped improve the final draft.

As Chairman, I would like to express a sincere thanks to the members of the Task Force, the Administrative Staff of the Hamilton-Wentworth District Health Council and especially our dedicated Research Assistant, Mrs. Barbara Rigby, for their enthusiasm and dedication towards the development of this report.

Yours sincerely,



D. J. Kraftcheck, M.D.,  
Chairman  
Palliative Care Task Force

DJK:ch



## TABLE OF CONTENTS

	<u>PAGE</u>
Table of Contents.....	i
List of Tables.....	iii
List of Appendices.....	iv
Palliative Care Task Force Membership.....	v
Executive Summary .....	vii
Chapter I - Introduction.....	1
1. Background.....	1
2. The Palliative Care Task Force.....	2
3. The Purpose.....	3
4. Goal/Terms of Reference.....	3
5. Methodology and Data Collection.....	4
6. Analysis of Data.....	6
7. Formulation of Recommendations.....	6
8. General Comments .....	6
Chapter II - Present State of the Knowledge.....	10
1. Definition of Palliative Care.....	10
2. Standards of Practice.....	10
3. Models of Care.....	12
4. Services Needed.....	13
5. Personnel.....	13
6. Eligibility Criteria.....	14
7. Economic Issues.....	15
8. Education.....	17
9. Research and Evaluation.....	18
Chapter III - Palliative Care in Hamilton-Wentworth - An Overview...	20
1. Components of a Definition of Palliative Care.....	20
2. Objectives of Palliative Care Programmes.....	21
3. Hospital Palliative Care Services.....	21
4. Home Palliative Care Services.....	33
5. Palliative Care Services Provided by Private Duty Nursing Agencies.....	39
6. Bereavement Follow-up Programmes.....	39
7. Palliative Care Services Provided by Community Support Agencies.....	40
8. Palliative Care in Nursing Homes.....	50
9. Hamilton and District Funeral Service Association.	51
10. Hamilton and District Christian Churches Assoc....	52
11. Palliative Care Education.....	52
12. Perceived Needs & Gaps in Palliative Care Services	55
13. Duplication of Services.....	55
14. Demographic Data.....	56



	<u>PAGE</u>
Chapter IV - Conclusions and Recommendations.....	74
1. Definition of Palliative Care .....	74
2. Standards of Practice.....	75
3. Models of Care.....	77
4. Services Needed.....	83
5. Types of Personnel.....	87
6. Eligibility Criteria .....	87
7. Economic Issues .....	88
8. Education .....	90
9. Research and Evaluation .....	91
References .....	94
Bibliography .....	98
Appendices .....	100



## LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
1.	Summary of the Compatability of Objectives of a <u>Sample</u> Regional Palliative Care Programme (East Central Illinois Health Systems Agency - ECIHSA <sup>8</sup> ) with Objectives of Individual Programmes in the Hamilton-Wentworth Region.....	23
2.	Summary of Hospital Palliative Care Services.....	28
3.	Summary of Home Palliative Care Services.....	34
4.	Summary of Private Duty Nursing Agencies' Palliative Care Services.....	41
5.	Summary of Bereavement Follow-up Services.....	44
6.	Summary of Palliative Care Services Provided by Community Support Agencies.....	47
7.	Summary of Data from Palliative Care Inventory Re: Unmet Needs and Gaps in Service.....	58
8.	Summary of Data from Survey of Family Practitioners Re: Unmet Needs and Gaps in Palliative Care Services.....	64
9.	Summary of All perceived Needs and Gaps in Palliative Care from Key Informants.....	68



## LIST OF APPENDICES

<u>APPENDIX</u>	<u>PAGE</u>
I. Palliative Care Questionnaire.....	100
II. Palliative Care Data Collection Tool.....	103
III. Family Physician Survey.....	108
IV. Palliative Care Administrative/Advisory Structure - St. Joseph's Hospital, Hamilton.....	109
V. Educational Involvement - Palliative Care Henderson General Hospital, Hamilton.....	113
VI. Educational Involvement - Palliative Care St. Joseph's Hospital, Hamilton.....	115
VII. Brief from Health Professions Coordination Group "A".....	116
VIII. International Standards of Care for the Terminally Ill.....	119
IX. Demographic Data.....	121
X. Operational Plan.....	126
XI. The Programmatic Approach.....	128



PALLIATIVE CARE TASK FORCE - MEMBERSHIP

Chairman:

Dr. D. J. Kraftcheck	Chief of Family Practice, St. Joseph's Hospital; Associate Clinical Professor Department of Family Medicine, McMaster University, Faculty of Health Sciences; and, Member of Hamilton-Wentworth District Health Council.
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Members:

Mrs. M. Baskin	President, Social Planning and Research Council.
Rev. D. Collier	Representing Hamilton and District Christian Churches Association.
Mr. S. Cowley	Director, Department of Social Work, St. Joseph's Hospital.
Dr. S. Eaman	Director of Adolescent Services, Chedoke Hospital Division, Chedoke-McMaster Hospitals; Assistant Clinical Professor, Department of Psychiatry, McMaster University.
Dr. G. K. Ingham	Clinical Professor, McMaster University; Clinical Director, Palliative Care Services, St. Joseph's Hospital; and, representative Hamilton Academy of Medicine.
Dr. E. Latimer	Assistant Professor, Department of Family Medicine, McMaster University; and, Director, Palliative Care Services, Hamilton Civic Hospitals.
Mr. K. Leslie	Administrator, Chedoke Hospital Division, Chedoke-McMaster Hospitals.

Mrs. D. Roe	District Director, Victorian Order of Nurses.
Dr. N. Thomson	Family Physician; Assistant Clinical Professor, Department of Family Medicine, McMaster University; Medical Advisor to the Home Care Program; and, representative, Hamilton Academy of Medicine.

Resource Persons:

Mr. S. Isaak	Assistant Executive Director, Hamilton-Wentworth District Health Council.
Dr. R. G. Kirby	Executive Director, Hamilton-Wentworth District Health Council.
Mrs. B. Rigby	Research Assistant, Palliative Care Task Force, Hamilton-Wentworth District Health Council.
Mrs. C. Hudson	Secretary





## EXECUTIVE SUMMARY

Palliative Care is a multi-disciplinary service which provides treatment and supportive care for terminally-ill patients and their families. Appropriate goals of care are symptom control, and physical, psychosocial and spiritual support, aimed at providing optimum quality of life. Care should be provided, as appropriate, in the home with the availability of hospital care when needed.

The report of the Palliative Care Task Force examines the local history of palliative care, the planning aspects for palliative care services and the means of providing palliative care services.

A major portion of the report describes the planning aspects described in the literature, the services presently available in the region and the perceived needs, gaps and duplications in palliative care services as identified by the key informants surveyed in the inventory. Also included is demographic data and morbidity and mortality statistics.

As a result of the analysis and interpretation of this data, the Palliative Care Task Force developed recommendations aimed at providing solutions to the identified problems.

Central to the recommendations is the establishment of a Regional Palliative Care Programme, whose structure, reporting mechanism and functioning would be similar to other regional programmes reporting to the District Health Council (See Appendix XI). This Regional Programme would be the logical body to oversee the implementation of the remainder of the recommendations, thus providing direction, coordination, with a direct communication link to the Health Council.

The report also includes an "operational plan" for the Regional Palliative Care Programme (Appendix X) which prioritizes the perceived needs and gaps in services, education and research to be addressed.

The recommendations include the definition and standards for palliative care for the region to provide a common basis for the development of eligibility criteria and the evaluation of services and education.

Recommendations are also made for the development of services in specific settings. The development or upgrading of multidisciplinary consultation teams in acute hospitals available throughout their institutions is endorsed. In addition, a support/resource group with an interest and expertise in palliative care for each team, the designation of palliative care units, and the strengthening of the Home Care palliative care services are recommended. The development/expansion of these services would be a major step in meeting palliative care service and education needs in the region.

Economic issues are addressed in the report. In view of the dearth of information available both in the literature and within the region, the report recommends a comprehensive cost-effectiveness study of palliative services in the region.

Ongoing evaluation of both institutional and community-based programmes is also endorsed to ensure that acceptable levels of care and education in terms of quality, consistency and continuity, are maintained.

Education and research are recognized as essential components of a comprehensive palliative care programme. Education must include the general public, patients and families, health professionals and volunteers in all settings. Professional education must occur in undergraduate, postgraduate and continuing education programmes to provide knowledgeable personnel.

The need for research is emphasized in the report. Several recommendations describe specific research projects to be implemented by the Regional Programme.

The recommendations, prioritized are:

1. The Task Force recommends the development of a Regional Palliative Care Programme similar to other regional, interdisciplinary programmes in Hamilton-Wentworth to address itself to the issues of palliative care service, education and research (Recommendation #8, page 85).

In addition, the Task Force recommends that the Regional Palliative Care Programme collaborate with other regional programmes, eg., Emergency Services and Oncology to provide more comprehensive services.

2. The Task Force recommends that a chair person be designated to coordinate palliative care services, education and research. In view of the time commitment involved in the formative years of the programme, the Task Force further recommends the funding of a half-time position - a Regional Coordinator - for at least three years (Recommendation #9, page 85).
3. The Task Force recommends that the following definition be accepted for Hamilton-Wentworth and that the definition be disseminated to all programmes/institutions/agencies providing service, education or research in the area of palliative care.

#### Palliative Care:

Palliative care is the active, compassionate care of the sick at a time when the goals of cure and prolongation of life are no longer paramount. The emphasis is on control of symptoms, and physical, emotional and spiritual care. It is multi-disciplinary in its approach, encompasses the patient, the family and the community in its scope and extends to include the bereavement process (Recommendation #1, page 75).

4. The Task Force recommends that the standards of the International Work Group on Death, Dying and Bereavement be adopted for Hamilton-Wentworth to be utilized as a basis for specific standards and objectives to be drawn up in each setting involved with palliative care services, education or research (Recommendation #2, page 76).



5. The Task Force recommends that the Regional Palliative Care Programme, through discussion with service providers, establish eligibility criteria for palliative care programmes throughout the region. These criteria should reflect the accepted definition and standards of the Regional Programme but allow for some diversity to reflect special interests as well as existing resources of individual programmes (Recommendation #11, page 88).
6. The Task Force recommends that St. Joseph's Hospital, and the Henderson General Hospital establish or maintain fully developed palliative care consultation teams in their institutions. It also recommends that the Hamilton General Hospital and McMaster University Medical Centre establish or maintain palliative care consultation teams to include an appropriate amount of physician, nursing, social work and chaplaincy services to meet the needs of palliative care patients in their institutions. These teams should be reviewed on an ongoing basis to ensure their staffing complement is adequate to meet the needs of these patients.

In addition, the Task Force also recommends that Chedoke Hospital and St. Peter's Centre continue to monitor the need for palliative care services in their institutions (Recommendation #4, page 81).

7. The Task Force recommends that palliative care services in the region include the strengthening of the Home Care palliative care programme with a more effective liaison with hospital consultation teams (Recommendation #7, page 82).
8. The Task Force recommends that the Board of Directors of each hospital be asked for a commitment to provide admitting policies that facilitate the admission of palliative care patients in an appropriately expeditious manner (Recommendation #6, page 82).
9. The Task Force recommends the development of a support/resource group by the palliative care consultation teams described in Recommendation 4. This group should consist of other health care disciplines, eg., pharmacy, physiotherapy, nutrition, with an interest and expertise in palliative care to provide services as needed (Recommendation #10, page 87).

10. The Task Force recommends that palliative care education be coordinated by the Regional Palliative Care Programme and include undergraduate, post-graduate and continuing education for health professionals including clergy and volunteers, in all settings as well as public education (Recommendation #13, page 91).
11. The Task Force recommends the designation of a palliative care unit environment and supportive staff in St. Joseph's Hospital, Hamilton Civic Hospital including the Hamilton General and the Henderson General, and Chedoke-McMaster Hospitals to care for the small percentage of palliative care patients needing specialized assessment and treatment and to serve as a focus for education and research. This development should occur in two stages, with units being established at St. Joseph's Hospital and Henderson General Hospital in the first phase and at Chedoke-McMaster Hospitals and Hamilton General Hospital in the second phase. A complete evaluation of the effectiveness of the units should be done at the end of the first phase before the development of units in the other hospitals (Recommendation #5, page 82).
12. The Task Force recommends that a structure for monitoring the implementation of standards for all palliative care service providers within institutions and agencies and especially within the community be established (Recommendation #3, page 77).
13. The Task Force recommends the development of a standardized data collection system to facilitate the audit of existing palliative care services, whether institutional or community-based (Recommendation #14, page 92).
14. The Task Force recommends the initiation of a comprehensive cost-effectiveness study of palliative care services in the region. It further recommends that the study be done under the auspices of the Regional Palliative Care Programme with the assistance of the Department of Clinical Epidemiology and Biostatistics at McMaster University (Recommendation #12, page 89).





## Chapter I

### INTRODUCTION

#### 1. Background

Palliative care has received increasing interest in recent years - both clinical interest and community interest - with the result that services of care for the terminally ill are being established in many different areas based on different models.

In Hamilton-Wentworth, there are three active treatment teaching hospitals with five divisions - St. Joseph's Hospital, Hamilton Civic Hospitals including Hamilton General Hospital and Henderson General Hospital, and Chedoke-McMaster Hospitals including Chedoke Hospital Division and McMaster University Medical Centre.

St. Joseph's Hospital, Henderson General Hospital and McMaster University Medical Centre have their own palliative care services. In addition, the Victorian Order of Nurses has a palliative care nursing team and the Home Care Programme, St. Elizabeth Visiting Nurses Association and Public Health Nursing section of the Hamilton-Wentworth Public Health Unit provide palliative care services as well.

Although the concept of palliative care extends to all patients with terminal illness, it is most often associated with terminally ill cancer patients. Oncology services in Hamilton-Wentworth are coordinated under a regional oncology programme which includes a supportive care group, encompassing some aspects of palliative care under its rubric.

The Cancer Clinic, itself, has as its focus cure-oriented treatment and due to limited resources has not developed a palliative care team of its own. Appropriate patients are referred to the palliative care team at the Henderson General Hospital for care.

As each service has developed separately, there has not been any coordination on a regional basis to ensure that the various component parts combine to provide an effective and efficient district programme. Nor has it been ensured that all of the component parts of such a programme are in place.

The concept of a district-wide programme is one which the Hamilton-Wentworth District Health Council has built on over the years to the point where virtually all clinical services are rationalized along the programmatic approach. The programmatic approach is a reorganization of health services from an institutional basis to a programmatic basis, in order to make the best use of limited resources in providing comprehensive health care (see Appendix XI for a detailed description of the programmatic approach).

There is considerable local interest in this issue, as evidenced by the fact that a group of individuals involved in palliative care in the above mentioned institutions and agencies have been meeting informally for a number of years. This group expressed a desire to see a coordinated district programme in palliative care established with a formal reporting mechanism to the District Health Council, similar to other regional programmes in this District.

## 2. The Palliative Care Task Force

Since one of the District Health Council's ongoing priorities is the continued refinement of the local health care system, utilizing a programmatic approach, it established a Steering Committee in July, 1982. Its mandate was to determine the feasibility of carrying out a detailed planning study for palliative care. The Steering Committee confirmed the interest of local institutions and community agencies in this area, and established the terms of reference and membership of the Palliative Care Task Force.

The Task Force included a mix of membership that would provide input from most sectors of the community involved in the delivery of palliative care. The Palliative Care Task Force began its deliberations in October, 1982.

3. The Purpose

This study will examine both the potential for coordination of the existing component parts and the need for other component parts to provide an effective efficient, coordinated district programme in palliative care and arrive at a plan for its provision in Hamilton-Wentworth.

4. Goal/Terms of Reference

a) Goal:

The Palliative Care Task Force, in providing the Final Report, has as its ultimate goal to provide a basis on which the provision of a coordinated district-wide palliative care programme may be planned and implemented.

b) Terms of Reference

1. To define the term "palliative care".
2. To review and evaluate the Ministry of Health Report on Palliative Care.
3. To classify and describe existing palliative care services in the Region.
4. To determine the need for the various components of a comprehensive palliative care programme in Hamilton-Wentworth.

5. To recommend what organizational arrangements and resources are necessary to provide a comprehensive palliative care programme.
6. To make progress reports to the Health Council and present the final report by June, 1983.

## 5. Methodology and Data Collection

Initially, the Palliative Care Task Force undertook two processes for accumulating data - a literature review and the compilation of a detailed inventory of palliative care services in Hamilton-Wentworth.

A computerized literature search was carried out to identify recent literature which examined the planning aspects, as opposed to the clinical aspects, of palliative care. A summary of this body of literature follows in Chapter 2 of this report.

The Ministry of Health Report on Palliative Care has not been released for the Task Force to review and evaluate but informal discussions were held with Ministry personnel concerning the report.

In order to ascertain the need for additional components of palliative care in Hamilton-Wentworth, the Palliative Care Task Force needed to be fully aware of and understand the scope of services already present in the community. The detailed inventory was carried out utilizing two methods - personal interviews and mailed questionnaires. Personal interviews were conducted with designated representatives of the five active treatment teaching hospitals, one chronic care hospital, four community health care agencies, five private duty nursing agencies, eight nursing homes, three homes for the aged and two community support groups. Also interviewed were representatives of the undergraduate, postgraduate and continuing education programmes for health professionals in the community.



Information from family practitioners concerning their perception of unmet needs and gaps in palliative care in the district was obtained by means of a mailed questionnaire.

Following consultation with the Department of Epidemiology at McMaster University, a survey of family practitioners was carried out. Since the total number of family practitioners within the district is approximately 270, and since response rate to mail surveys is approximately 30 to 40% at best, it was decided that there was little opportunity of showing a statistical difference between the two designated groups - solo and group practitioners. The option of obtaining descriptive data regarding palliative care needs rather than inconclusive statistical information was selected.

The family practitioners from each hospital were divided into two groups according to their type of practice - group or solo. Subjects were selected by a process of simple randomization. Questionnaires were sent out to 33 solo practitioners and 45 group practitioners. This was followed by a second mailing. Fifty-nine practitioners (76.5%), in total, responded.

Briefs were submitted by the Hamilton and District Funeral Service Association, the Hamilton and District Christian Churches Association and Health Professions Coordination Group "A" of the District Health Council delineating their perceptions of needs and gaps in palliative care services in Hamilton-Wentworth.

Finally, the Task Force reviewed relevant population data to gain insight into the extent to which palliative care services are currently needed and to make projections into the future.

6. Analysis of Data

The Task Force examined the planning aspects of palliative care described in the literature; the services available in the region, the perceived needs and gaps in palliative care services identified by the key informants surveyed in the inventory and the population data. In this manner, the integration of general methodologies and specific information allowed for a more comprehensive assessment of the delivery of palliative care services in the region.

As a result of the analysis and interpretation of the collated data, specific issues relating to unmet needs and gaps in services were identified. A summary of this information is included in Chapter 3 of the report.

7. Formulation of the Recommendations

The examination of these issues in light of the goals and objectives of the final report of the Palliative Care Task Force, led to (1) a critical review of alternative courses of action and (2) recommendations aimed at providing solutions for the identified problems.

8. General Comments

The growth of interest in palliative care services has come from a perceived need for more comprehensive care for terminally-ill patients. The need has been observed by all disciplines of health professionals, community support groups and the general public.

The response to this need has been the development of groups of individuals within institutions and community agencies with interest and growing expertise in palliative care who are attempting to provide adequate services for this group of patients. These individuals have come to provide service and education for other health professionals and volunteers as well.

The development of the art and science of palliative care into a specialty area is probably one point on the continuum of improving overall health care services. Once the group of professionals with expertise in the area of palliative care have demonstrated through service provision, education and research, the ability to provide high quality care to terminally-ill patients, the responsibility for care can be returned to all health care workers with only a core group left to provide support, education, research and care to a very limited group whose problems require consultative care.

Dr. John Scott (27) makes several points. First, it is very difficult to define the patients who could most benefit from palliative care or indeed, who are 'dying'. Second, is that the complexity of current treatment for malignancies makes it difficult to know who will no longer respond to active therapy. Finally, there are many patients with diseases other than cancer who may have greater needs but are excluded from palliative care services. Based on these facts, Dr. Scott indicates the need for the integration of hospice principles into mainstream medicine, both into education and delivery of care systems.

The concept of re-integration of palliative care into mainstream health care is also supported by Parker Rossman who states, "It has been suggested that the New Haven Hospice, and perhaps all such programs should be developed with planned obsolescence as the ultimate goal....For the "model" idea intends to demonstrate not only better ways of taking care of terminally-ill persons but also point out one way in which health care structures of the country can be helped to move in new directions which will make hospice services unnecessary, for they will then be implicit in all health care programs and services."(24).

The Palliative Care Task Force recognized this possibility of planned obsolescence and included it in its examination of issues leading to the recommendations in the report.

The Task Force, in carrying out its inventory, was not able to tap two very important sources of information concerning palliative care services. First are the patients and/or families who have received palliative care services. Second are the volunteers who are associated with the various institutions, agencies and community support groups within the region. Informative data from these groups could only be attained by sophisticated research tools and study designs which were beyond the scope of this Task Force.

The Task Force recognizes, however, the ongoing need for input from these groups as palliative care services develop within this region. As well, the importance of mobilizing the resources and support within family circles and within volunteer groups, community support groups and self-help groups is recognized.

Recognition is also given to the amount of time and supportive care given by volunteers to terminally-ill patients. The quality of palliative care in the region would be much lower without their service.

The need for bereavement follow-up was an issue frequently identified in the inventory. At the time of death, the focus moves from the patient and family to the family alone. Care at the time of bereavement should ideally come from the family's own support system within the community. Health professionals need not be involved except in the case of high risk individuals and/or families.

While the report introduces these issues, the Task Force recognized that a full discussion of their implications was beyond the scope of this study. It is for this reason that the emphasis of this report is on the establishment of a regional programme in palliative care, one of the tasks of which will be to address each of these issues in fuller detail. This report, then, provides a basis on which the provision of a coordinated district-wide palliative care programme may be planned and implemented.

Recognizing current economic restraints within the health care system the Palliative Care Task Force opted to make recommendations for the development of a staged programme. The first stage involves the integration of present services at a low cost to meet short term goals for improvement of palliative care services. The second stage will involve the development of long term goals for new programmes and/or facilities. The Task Force recognizes that this planning must be flexible and responsive to proven needs within the district.

The fourth chapter of the report presents the recommendations of the Task Force accompanied by the rationale for the recommendations.





## Chapter II

### PRESENT STATE OF THE KNOWLEDGE

A recent search of the literature reveals a considerable body of information which examines the planning, as opposed to the clinical aspects, of palliative care. The literature identifies nine main areas for consideration in the planning of palliative care services. These are: (1) definition of palliative care; (2) standards of practice; (3) models of care; (4) services needed; (5) types of personnel needed to provide the services; (6) eligibility criteria for the services; (7) economic issues; (8) education; and, (9) research and evaluation.

#### 1. Definition of Palliative Care

The definition of "palliative care" varies with the source but has a number of components which are consistent throughout most definitions. These include: (1) programmes or services that provide care to those for whom treatment aimed at cure is no longer appropriate but for whom therapy is aimed at improving the quality of remaining life (12, 13, 15, 17, 20, 29); (2) therapeutic services that address the physical, psychosocial and spiritual needs of patients families (12, 13, 15, 17, 20); (3) the patient and family as the unit of care (12, 13, 15, 17, 20, 29); (4) the coordination of care by a multi-disciplinary team that includes health care professionals, (with active physician involvement) patient, family and volunteers (12, 13, 15, 17, 20, 29); (5) the fact that palliative care is ideally made available for the patient and family on a 24 hours - 7 day/week basis from the time of diagnosis of terminal disease until death and to the family after the patient has died (13, 15, 21).

#### 2. Standards of Practice

Four main areas have been delineated as essential in planning standards for palliative care (14, 23). First and foremost are patient-oriented standards that will provide comprehensive care for the patient in the terminal stages of life. Included are such areas as symptom control,

continuity of care, need for information and respect for the patient's belief system.

Second are the family-oriented standards that provide for time, information, support and understanding to be made available to families and significant others during the terminal stages and following bereavement.

Next come staff-oriented standards which revolve around such issues as staff education and support.

Finally are standards governing the administrative role and provision of services. These issues include coordination and distribution of programmes and services in the areas of medical management of patient, supportive services to the patient and family, educational services, research and establishment of an effective decision-making process. Evaluation of services is another issue with which administrative standards must be concerned. The literature provides general guidelines or standards because as Mount states, "that while institutions need guidelines to develop standards, each setting must develop its own standards based on certain key assumptions and principles." (23)

### 3. Models of Care

A number of models have been identified. Services can be provided in institutions, in the community and some models combine both settings to provide more continuity of care for the patient.

The identified models for delivery of palliative care include:

1) a physically and economically independent facility or hospice, eg., St. Christopher's, London, England; St. Columba's, Edinburgh, Scotland; and, the Brandford Hospice at New Haven, Connecticut (13, 16, 24).

- 2) a hospital-based palliative care unit designed, equipped and staffed to meet the needs of the terminally ill patient, eg., Royal Victoria Hospital PCU, Montreal; and Hospice Victoria at Royal Jubilee Hospital, Victoria, B.C. (13, 14, 16, 24).
- 3) a palliative care team in an acute care hospital to act in a consulting capacity as well as giving direct care, eg., St. Luke's Hospital, New York; St. Thomas-Elgin General Hospital, St. Thomas, Ontario (6, 13, 16, 28).
- 4) a palliative care team for the terminally ill at home. This may be associated with a hospice or palliative care unit or with an existing Home Care Programme, eg., New Haven Hospice, Royal Victoria Hospital, Montreal; St. Boniface General Hospital, Winnipeg (12, 13, 16).
- 5) palliative care in chronic hospital, eg., Salvation Army Grace Hospital, Toronto; Riverdale; (16, 24, 27).
- 6) palliative care in nursing homes, eg., Washington Home, Washington, D.C., Sisters of St. Rose Hawthorne, New York (16, 24).
- 7) palliative care in a day care setting. This provides care and/or services, eg., physiotherapy for a few hours or can replace family member while working, eg., Hillhaven Hospice, Tucson, Arizona (9, 12, 16, 24).
- 8) palliative care by commercial health care services, eg., Comcare, UpJohn, Paramed (16).
- 9) wholly volunteer services (6).

A number of combinations of these models also exist, eg., Royal Victoria Hospital; PCS, Montreal.

Consideration has also been given to regional hospice networks that involve multi-institutional and agency arrangements to provide high quality care and to plan for coordination and distribution of services on a regional basis (9, 10).

Benefits and problems associated with the various types of programmes are also addressed in the literature (16).

#### 4. Services Needed

Another issue addressed is the type of services needed for terminally ill patient, families and for caregivers. Included in these services are the need for: (1) inpatient care for patient and family on a 24 hour/day 7 day/week basis, (2) outpatient care for patient and family on a 24 hour/day 7 day/week basis, (3) skilled symptom control, (4) multi-disciplinary team, (5) access to acute care facilities, (6) medical and nursing consultation in hospitals and at home, (7) education of patient and family, (8) education of staff, (9) structured staff support mechanisms, (10) bereavement follow-up, (11) evaluation of services, (12) research, and (13) mechanisms for communication and liaison between the services in institutions and agencies in the community (9, 12, 13, 15, 21).

#### 5. Personnel

In addition, the types of personnel necessary to provide the desired services have also been described. Many indicate the need for physician directed services (12, 15, 24). A Clinical Nurse Specialist to act as a consultant, educator, liaison, coordinator of care and a support person for staff has also been identified as a necessity (6). Other nursing personnel are essential in the provision of high quality palliative care, both in institutions and in the community (15, 21, 24).



The Social Worker is the third most frequently identified member of the palliative care team followed by the clergy and various other members of the health care team (occupational and physiotherapists, dietitians, pharmacists, recreational and music therapists) (7, 15, 24).

The value of volunteers is emphasized in much of the literature as being essential to the continuity of care for terminally ill patients (5, 7, 12, 15, 24). They may be involved in direct patient and family support and care or in indirect services such as shopping or babysitting. All require appropriate training and support.

The emphasis in the literature is on team work among the individual professions with recognition that all disciplines are not necessary for the care of all patients. Role overlap must be accepted.

Fragmentation of care must be avoided and an attitude of cooperation maintained. As Lack states, "There is no room in terminal care for interagency rivalries or interdisciplinary turf guards" (15).

#### 6. Eligibility Criteria

A number of articles also identify eligibility criteria for palliative care programmes. The first criterion is a decision made by the physician in conjunction with the patient and family that the patient is in the terminal stages of life and that the treatment goal should be maintenance or improvement of the quality of life rather than cure of disease or prolongation of life. The length of time until death is a variable issue with some indicating as little time as a few days and some as long as a year or more before death as appropriate for admission to service. All indicate that admission to service should be on the basis of health care need, not on the ability to pay. A number of programmes specify that the patient must have cancer to be admitted, eg., Calvary Hospital, New York and the New Haven Hospice. Other acknowledge the need for other patient groups - end-stage heart, renal, respiratory, diabetic and neuromuscular disorders to be included. Some programmes specify that patients and families

must live within the geographic area the programme is able to serve. Preference is frequently given to those patients whose symptomatology is out of control. The criteria for admission to palliative care programmes must of necessity be unique to each service depending upon its philosophy and the resources available to it, for no programme can service all patients who might apply for help (9, 13, 24, 26, 29).

## 7. Economic Issues

Another area for consideration centres on economic issues including such concerns as bed/population ratio, staff to patient ratio, terminal care delivery costs and funding sources. Information on these areas is quite limited, especially from Canadian sources.

Mount and Ajemian (21) from their experience at the Royal Victoria Hospital indicate that a general hospital with an active oncology service and with a consulting team and a home care programme may have a need for 2-3 beds per 100 acute beds. The number of nursing care hours per day per patient on the palliative care unit is on an average 6.1 hours - a staff to patient ratio slightly higher than on general medical-surgical units, but lower than their projected 9 hours of care. They also indicate that the small increase in costs related to increased staff to patient ratio was offset by savings obtained by the reduction in the number of investigations on patients on the unit.

From a careful analysis of the status of patients on their Home Care Programme over a three month period, Mount and Ajemian (21) suggest that half of the patient days on the Home Care Service would be in-hospital days if the service did not exist.

LePine (16), in her report, states that the Royal Victoria Hospital over its first five years of its home care programme recognized savings of almost \$7,000 per patient and that between July 1979 and March 1980, about 3,209 inpatient days were avoided because of the service, a savings

of \$276 per day. She indicates that the net savings to the health system, over this five year period by the operation of the Home Care Programme was approximately \$636,784.

From data obtained from the Palliative Care Unit at the Grace Salvation Army Hospital, Toronto, by the Government of Ontario, it was estimated that the per diem costs for patients in the unit were about one third of costs in an active bed -- \$107 versus \$304 per patient day at Princess Margaret Hospital.

LePine (14), using the U.K. standard of .025 terminal beds per 1000 population, indicates the need for 600 beds across Canada.

At present, two out of three cancer patients die in hospital in Canada. By promoting home care programmes so that two out of three can elect to die at home, LePine projects net cost-savings would be at least \$210 million per annum. By combining a national home care programme with the development of special palliative care units in hospitals, she projects a net cost savings in excess of \$700 million per year.

The search of the literature revealed two studies done in the United States that also suggest the potential for substantial cost savings following the introduction of integrated palliative care services. Amado, Cronk and Mileo (1) reported on the cost effectiveness of a Blue Cross-funded demonstration of routine and extended home care services for 55 dying patients. The authors reported a savings of 943 in-hospital days and a cost savings of \$93,549 or approximately \$1700 per patient. They caution that for this type of programme to be successful third-party payers must accept the idea that home care is an appropriate level of care.

The study by Bloom and Kissech (3) of nineteen matched pairs of terminal patients reported a 10.5-fold difference between the mean total 2-week charges incurred by those dying at home and those dying in hospital. The mean per diem cost for those dying at home was \$42. For those in hospital, it was \$441 per diem.

The literature indicates that funding for Palliative Care Services comes from a variety of sources, both public and private (1, 3, 6, 15). A substantial amount for home and hospital care in Canada comes from government funding. Private insurances and organizations such as the Canadian Cancer Society provide additional funding for patients in the home. Some programmes such as the Windsor Hospice are supported by community donations.

The literature dealing with economic issues indicates the costs of terminal care in hospital are substantial and suggests that integrated palliative care programmes consisting of home care and inpatient services could substantially reduce health care costs for this group. However, the assessment of economic issues is, at best, limited and a detailed economic assessment would be necessary to determine if these preliminary findings are accurate and the projected savings could occur.

#### 8. Education

Much of the literature indicates a need for education of health personnel of all disciplines, at all levels of experience, as well as for patients, families and volunteers. The recognition of this need and the inclusion of education is an essential element in planning palliative care programmes.

The standards set down by the International Work Group on Death, Dying and Bereavement (20) include those dealing with the need to educate and update patients, families and palliative care staff. For health professionals, education must occur on several levels. The first is education for all disciplines in all areas of health care to heighten awareness of the needs of terminally ill patients and their families (29). The second relates to the education and training of all staff members and volunteers at the time of employment in palliative care (5, 21, 29). The third is continuing education on a regular basis to keep health care personnel abreast of new developments in the area of palliative care (13, 21, 29). Education needs to occur in both under and postgraduate programmes in all disciplines involved in palliative care to sensitize health care students to dying, death and grief processes, to further understanding of terminal care concepts and to inculcate sound palliative care methodology (13, 21, 29).

Conferences, lectures, seminars, discussion groups, workshops, service rounds, student electives, residency rotations and inservice education have all been identified as methods of dispersing palliative care information as well as one to one consultations between health professionals.

Education service has been an integral part of the leading programmes both in Britain and Canada, with St. Christopher's, St. Columba's and the Royal Victoria Hospital Service all placing strong emphasis on meeting the educational needs of health professionals and volunteers (13).

9. Research and Evaluation

The final area for consideration in palliative care planning is research. The literature identifies two areas for consideration. One is evaluation of present services including evaluation of staff and volunteers, of services rendered and of programmes' effectiveness (2). The second is controlled scientific research into a number of issues surrounding palliative care. The efficacy and effectiveness of palliative care services, as with all other health care services, need to be assessed. Cecily Saunders, M.D. indicates the need for research to provide positive proof of the value of hospice care if it is to gain acceptance in the health care field (19).

Walter Spitzer, M.D. cites the need for randomized clinical trials to validate the worth of palliative care (19). A multitude of clinically-based questions need scientific research to clarify them, eg., pain and symptom control agents and methodologies. Research is also needed in the area of education to determine the value of curriculum changes and educational programmes for health care professionals and training programmes for volunteers (12, 19). Again, St. Christopher's, St. Columba's and the Royal Victoria Service identify research as an essential component of their services.



In summary, many of the issues involved in the planning of palliative care services are well delineated in the literature with the exception of the economic issues which require further research to support the pilot findings. Information regarding coordination of regional programmes is also quite limited. Except for these two areas the literature provides a good data base for planning of palliative care services in a coordinated manner.

### Chapter III

#### PALLIATIVE CARE IN HAMILTON-WENTWORTH - AN OVERVIEW

The inventory of palliative care services undertaken by the Palliative Care Task Force included 19 agencies/institutions within the District. In addition, briefs were presented by the Hamilton District Funeral Service Association, the Hamilton Christian Churches Association and the Health Professions Coordination Group "A" of the District Health Council. The Task Force also undertook a survey of family practitioners and a review of relevant population data. For a full description of each of these data sources, see the Introduction to this Report. The data is summarized in the following sections.

##### 1. Components of a Definition of Palliative Care

Although the definitions of palliative care varied among the key informants surveyed, there were components that were common to all of the definitions. These were:

- 1) an incurable disease entity,
- 2) no active investigation, diagnosis or intervention directed at cure of disease,
- 3) symptom management is the focus of medical investigation, diagnosis and intervention,
- 4) provides physical, psychosocial and spiritual care,
- 5) patient has limited life expectancy,
- 6) involves support for the patient, family and significant others,
- 7) emphasizes dignity and quality of life,
- 8) utilizes a multidisciplinary team for care including professionals, non-professionals and volunteers,
- 9) includes support mechanisms for the care giver,
- 10) involves bereavement follow-up for the family, and
- 11) presupposes information-sharing with the patient and family and their involvement in the decision-making process.

## 2. Objectives of Palliative Care Programmes

Five institutions/agencies in the Hamilton-Wentworth area have palliative care services with specific objectives defined. The comparability of these objectives with the objectives of a sample regional palliative care programme is demonstrated in Table 1. There appears to be considerable similarity amongst the objectives of the individual programmes in the region. These objectives can also be integrated easily with the objectives of the sample regional programme.

## 3. Hospital Palliative Care Services

Table 2 demonstrates the comparability of palliative care services in Hamilton's five acute care hospitals and one chronic hospital on the variables: description of programme, eligibility criteria and utilization of services.

Three of the five acute care hospitals (St. Joseph's, McMaster University Medical Centre and Henderson General) have formalized palliative care services providing consultation, counselling, education and bereavement follow-up. Hamilton General and Chedoke Hospital as well as St. Peter's Centre have no designated palliative care programmes but do provide some services to palliative care patients.

The hospitals' palliative care teams are fairly consistent as to: (1) definition of palliative care, (2) objectives of teams (3) model of care - a palliative care consultation team, (4) types of services provided, (5) eligibility criteria, (6) educational function, and (7) research and evaluation of present services.

There is a wide variation in the number of administrative/advisory groups, from no designated palliative care group at the Hamilton Civic Hospitals, through palliative care interest groups at Chedoke Hospital and St. Peter's Centre, a Palliative Care Committee at McMaster to several committees at St. Joseph's Hospital.

Composition of the palliative care team varies considerably from institution to institution. St. Joseph's has two full time staff - a registered nurse who acts as coordinator and a social worker. A medical oncologist serves as medical director and a consultant on a part-time basis. The service has a secretary on a half-time basis. A clergy liaison and volunteers are also available.

McMaster has a full time registered nurse acting as coordinator with access to all other hospital services. A medical oncologist is available to the team on a consultation basis. A minimal amount of his time is available for palliative care.

All members of the team at the Henderson General, including the physician, social worker, clergy and secretary work on a part-time basis.

Only McMaster attempts to provide coverage on a 24 hour/day 7 day/week on-call basis which is very difficult with only one full time team member.

Funding sources also vary from a specific palliative care budget at St. Joseph's to funding from departmental budgets at McMaster.

The final area for comment in the hospital data is that, although there is no direct cost to the patient or family for palliative care services providing they have O.H.I.P. and/or other insurance coverage, there are a number of indirect costs. These indirect costs include such things as loss of income for spouse and/or other relatives, parking fees, meals at hospital if remaining with the patient for prolonged periods, babysitting and help in the home.

TABLE 1

SUMMARY OF THE COMPATIBILITY OF OBJECTIVES OF A SAMPLE REGIONAL

PALLIATIVE CARE PROGRAMME

(EAST CENTRAL ILLINOIS HEALTH SYSTEMS AGENCY - ECIHSA<sup>8</sup>)

WITH OBJECTIVES OF INDIVIDUAL PROGRAMMES IN HAMILTON-WENTWORTH REGION

ECIHSA PROGRAMME OBJECTIVES	PALLIATIVE CARE OBJECTIVES OF INSTITUTIONS/AGENCIES IN HAMILTON-WENTWORTH REGION*	NAME OF INSTITUTION/ AGENCY
Overall goals:		
1. In the short range, to cooperate to provide the resources and expertise for high-quality, cost-effective hospice care in three current programmes	To assist the primary care givers in the hospital and community to provide optimum care to terminally ill patients and their families who relate to St. Joseph's Hospital.	St. Joseph's Hospital
	The development of a functioning Palliative Care Consultation Team within the Civic Hospitals for the provision of consultative care to the dying patient and his family.	Hamilton Civic Hospitals
	To coordinate palliative care within the institution, identify the needs of patients and staff and make recommendations to the Palliative Care Committee; to provide direct clinical service to specific patients and families and to provide support to staff working with palliative care patients.	Chedoke- McMaster Hospitals
	To deliver comprehensive quality health care to each patient and family by establishing policies, procedures and standards of care of the terminally ill patient.	Victorian Order of Nurses
	To enhance the quality of life for terminally ill patients who have chosen to die at home	Public Health Nurses
2. In the long	To assist with the development	St. Joseph's



Table 1, continued

ECIHSA PROGRAMME OBJECTIVES	PALLIATIVE CARE OBJECTIVES OF INSTITUTIONS/AGENCIES IN HAMILTON-WENTWORTH REGION*	NAME OF INSTITUTION/ AGENCY
term, to ensure access to hospice care throughout the region	of a coordinated regional hereave-ment programme for survivors.	St. Joseph's Hospital
	Continued involvement in the Regional Palliative Care Interest Group which is comprised of representatives from each agency and hospital involved in the care of the dying. The mandate is to identify and coordinate the palliative care needs of the community on a regional basis.	Hamilton Civic Hospitals
	To represent the institution at the Regional Palliative Care Committee meetings	Chedoke-McMaster Hospitals
Objectives:		
1. To establish a coordinating steering committee that will meet regularly to exchange ideas and experiences		
2. To diffuse hospice services to other parts of the health service area	To assist primary care givers in hospital and community to provide optimum care to terminally ill patients and families who relate to St. Joseph's Hospital and to provide support mechanisms for caregivers of terminally ill patients	St. Joseph's Hospital
	The development of a collaborative relationship with community-based caregivers, eg. V.O.N., Home Care, St. Elizabeth Nurses, Public Health Agencies, Community physicians etc.	Hamilton Civic Hospitals
	To act as a consultant to other departments on matters dealing with the care of palliative patients and to work as a liason with community resources so that patient care is	Chedoke-McMaster Hospitals

Table 1, continued

ECIHSa PROGRAMME OBJECTIVES	PALLIATIVE CARE OBJECTIVES OF INSTITUTIONS/AGENCIES IN HAMILTON-WENTWORTH REGION*	NAME OF INSTITUTION/ AGENCY
	coordinated and admission and discharge to and from the hospital takes place with ease	
	To maintain effective working relationships with other disciplines and V.O.N. nurses	Victorian Order of Nurses
	To maintain effective cooperation and collaborative relationships with other disciplines and community nursing services	Public Health Nurses
3. To share a programme of continuing education for hospice members	To provide educational services aimed at disseminating the practice, methods, standards and philosophy of palliative care to health care staff in hospital and community; students of various disciplines and terminally ill patients and their families	St. Joseph's Hospital
	The provision of education to Medical, Nursing, and Social Work staff within the Civic Hospitals; the education of students in the Health Sciences - undergraduate and postgraduate - in the philosophy and science of palliation. The education of other disciplines, eg.- social work, chaplaincy etc., will also be included where appropriate	Hamilton Civic Hospitals
	To work with Patient Care Coordinators Clinical Teachers and Clinical Managers to develop an educational thrust consistent with the philosophy of palliative care and to participate in educational programmes of the Faculty of Health Sciences and in other programmes preparing professionals in accord with his/her clinical expertise	Chedoke-McMaster Hospitals
	To provide an atmosphere of learning	Victorian

Table 1, continued

ECIHSa PROGRAMME OBJECTIVES	PALLIATIVE CARE OBJECTIVES OF INSTITUTIONS/AGENCIES IN HAMILTON-WENTWORTH REGION*	NAME OF INSTITUTION/ AGENCY
4. To collaborate in developing treatment protocols for patients and their families	and staff development through orientation, continuing education and support programmes for members of the team	Order of Nurses
	To provide general education about grief and loss to specific target populations, eg. school children, organizational groups.	Public Health Nurses
	As for objective 2; to provide a bereavement follow-up programme aimed at prevention & reduction of negative consequences of grief & to provide a volunteer service for palliative care patients	St. Joseph's Hospital
	To continue to develop the Palliative Care programme through the interpretation and implementation of policies and procedures and to recommend changes in practice and/or procedures to accommodate palliative patients	Chedoke-McMaster Hospitals
	To demonstrate an understanding of the patient with a terminal illness and the impact of illness on the family; to provide quality care to terminally ill patients that enables the patient to remain an active family member if he/she wishes and to ensure patient participation in decision-making wherever possible	Victorian Order of Nurses
	To provide comfort and relief in controlling the patient's distressing symptoms ( physical, psychological, interpersonal and spiritual); to demonstrate an understanding of the individual with terminal illness and the impact on the family; to assist individuals with successful grieving & to identify individuals and families who exhibit morbid grief reactions	Public Health Nurses

Table 1, continued

ECIHSa PROGRAMME OBJECTIVES	PALLIATIVE CARE OBJECTIVES OF INSTITUTIONS/AGENCIES IN HAMILTON-WENTWORTH REGION*	NAME OF INSTITUTION/ AGENCY
5. To develop an evaluation methodology, including uniform data collection with assistance from University of Illinois	The initial assessment of Palliative Care needs of the Hamilton General Hospital and Henderson General Hospital. This assessment will provide for effective resource identification and allocation	Hamilton Civic Hospitals
	To set up a method for collection of statistics and evaluation of the programme	Chedoke-McMaster Hospitals
	To monitor standards of nursing performance through regular evaluation with nurses on the team	Victorian Order of Nurses
6. To develop research methodology in conjunction with University of Illinois	Research in palliative care - to identify and plan to meet the needs of (1) the patient and his family, (2) the Civic Hospitals, (3) the community	Hamilton Civic Hospitals
	To identify research in the area of palliative care	Chedoke-McMaster Hospitals
	To participate in research which contributes to the improvement of care for the terminally ill patient and his family	Victorian Order of Nurses
7. To cooperate in community public relations programme	Education of the public	Hamilton Civic Hospitals
8. To jointly investigate financial reimbursement for hospice service		
* Refers to Institutions/Agencies with specific palliative care programmes with set objectives.		

TABLE 2

## Summary of Hospital Palliative Care Services

Items	Henderson	St. Joseph's	McMaster Division	General	Chedoke Division	St. Peter's
DESCRIPTION OF PROGRAMME						
Administrative/ Advisory Group	No palliative care committee	See Appendix IV	Palliative Care Committee	None	Palliative Care Concern	Interest group on terminal care
Type of Services	Consulting, Counselling, Education, Bereavement Follow-up	Consulting, Counselling, Education, Bereavement Follow-up	Consulting Counselling, Education, Bereavement Follow-up	None	Consulting, Counselling, Bereavement Follow-up	None
Membership	1 M.D.-.5 1 S.W.-.7 1 Clergy-.6 1 Secretary-.3	1 M.D.-.25 1 R.N.-ft 1 S.W.-ft 1 Secretary-.5 Clergy liason	1 M.D.- pt 1 R.N.-ft 1 S.W.-pt 1 Chaplain-pt	No program	No designated programmes	1281
	Access to all other services within the institution	Access to all other services within the institution	Access to all other services within the institution		Access to all services within the institutions	
	Volunteers-0	Volunteers-16	Volunteers-6			
Funding Source	M.D.- .5 from Dept of Family Medicine, .5 OHIP billing + Supplement from Civics until June 1984	Hospital P.C. Budget	R.N.- from Dept of Nursing Dept budgets		Services for palliative care patients - as other patients	

Table 2, continued

Items	Henderson	St. Joseph's	McMaster Division	General	Chedoke Division	St. Peter's
Cost to Client	No direct cost	No direct cost	No direct cost		No direct cost to client	
Cost to Agency	Unknown	Unknown	Unknown		Unknown	Unknown
Average # Care Hours	3/4-1 hr/day	1/2-3 hr/day	2-3 hr/day		As other patients	
Staff Support	Chaplain, S.W., M.D. - group or individual counselling on an inci- dental basis Weekly team meetings	Informal 1 to 1 daily Formal- nursing units- 1 hr/2 wks	None formalized		None formalized	
Expansion/ Reduction	R.N. Volunteers 1/2 day OP clinic at the Cancer Clinic Expanding BF program	C.N.S. Added secret- arial hours	Formulating Report to PC for further direction		Terminal care group to assess needs and make recommendations	
Education	See Appendix V	See Appendix VI	Inservice Supervision of chaplaincy, S.W., students + 2 Residents		Seminars Conferences for gp members	
Research	None	None	None		None	None



Items	Henderson	St. Joseph's	McMaster Division	General	Chedoke	St. Peter's
Evaluation of Services	Ongoing data collection	Ongoing data collection	Stats to be computerized		None	None
Access to Hospital Beds for O.P	Prebooked ER No priority status for P.C. patients	ER No specific beds for admission	Prebooked ER Sticker for chart to indicate P.C. patient near end of terminal stage		Depending on need Urgent cases immediately	
ELIGIBILITY: INCLUSION AND EXCLUSION CRITERIA						
Diagnosis	Any-mainly Ca	Any-mainly Ca	Any- mainly Ca		Any	Any
Prognosis	Grey area- varies with reason for consultation	Grey area-no definite # of weeks	Grey area-no definite # of weeks		3-6 months	Grey area-no definite# of weeks
Age	Adults	Adults	Adults- Paeds has own team		Adults	Adults
Sex	Either	Either	Either		Either	Either
Referrals	Any source Mainly R.N., M.D.	Any source Mainly R.N. M.D.	Any source Mainly R.N., M.D.		Any source	Any source M.D., Home Care, Acute Hospitals
Language & Cultural Barriers	Access to sensitive interpreters is often a problem when the patient nor family speak English					
Geographic Area Served	Hospital catchment	Hamilton Wentworth	Hospital catchment		Hospital catchment	Hamilton-Wentworth Joseph Brant

Table 2, continued

Items	Henderson	St. Joseph's	McMaster Division	General	Chedoke	St. Peter's
Access to move Cure-Care	No difficulty	No difficulty	No difficulty		No difficulty	No difficulty
UTILIZATION						
Capacity	Approximately 20/month with present staff	10-12/week	15-20/month		No formal programme	Depends on needs of patients
Coverage	8-7pm/5days/wk After hour availability as indicated by need	R.N. & S.W- 8hr/day/5day/wk M.D.-5day/wk, 1 weekend in 4	24 hr on call		Responds as need arises	24hr care
Waiting list	No	No	No		No	No
Time lapse from Referral	From minutes to 2 days dependent on needs	From minutes to 2-3 days dependent on needs	Usually 24 hrs		None	N/A
Admissions	M.D.- total visits 361 No stats for clergy or S.W. July '82-Jan. '83	242 (1982)	No stats		No stats	No stats - 12 pts at present- about average #
Average Length of Stay	2-3 weeks	4-6 weeks	3 months		No stats	3 months

Items	Henderson	St. Joseph's	McMaster Division	General	Chedoke	St. Peter's
Referrals to Service	G.P.'s, Internists, nurses, clergy, ( Surgeons low numbers)				No programme	Home Care, Acute hospitals, M.D.
Referrals From Service	Home Care, Public Health, Cancer Society, Clergy, Psychiatrists, Red Cross				No programme	Acute hospitals
Death/Discharge	No stats	No stats	No stats		No stats	50% deaths

#### 4. Home Palliative Care Services

Table 3 demonstrates the compatibility of palliative care services in Hamilton's four home health care agencies on the variables: description of programme, eligibility criteria, and, utilization of services.

The four agencies (Home Care Programme, Victorian Order of Nurses, St. Elizabeth Visiting Nurses' Association, Public Health Nursing) provide palliative care services in the home. Home Care provides a multidisciplinary service, while the other three agencies provide home nursing services. Home Care, Victorian Order of Nurses, and St. Elizabeth's provide more direct patient care in addition to counselling, patient education and bereavement follow-up while the Public Health Nurses emphasize the latter three. The Home Care Programme provides the coordination of multidisciplinary services and contracts with the other agencies for nursing services. Only the Victorian Order of Nurses has a designated Palliative Care Team providing home nursing care. Public Health Nursing is developing a Bereavement Follow-up Team to provide support for high risk spouses and families. This is described in Table 4.

Presently very little statistical information specific to palliative care is available concerning per diem cost to the agency, average number of care hours, admissions, average length of stay or discharges from service.

Only the Victorian Order of Nurses' Palliative Care Team has admission and discharge statistics specific to palliative care available at the present time.

The home health care agencies are quite consistent as to: (1) definition of palliative care, (2) objectives of their services, (3) administrative structure, (4) eligibility criteria, and (5) education.

TABLE 3

## Summary of Home Palliative Care Services

Items	Home Care	St Elizabeth's	V.O.N.	Public Health
Administrative/ Advisory Group	None at present specific to pall- iative care	Health Care Advisory Committee; None at present specific to palliative care	Service Advisory and Medical Advisory Comm- ittees of the V.O.N. Board of Management, Hamilton- Dundas Branch For the pilot palliative care project	None at present specific to palliative care
Types of Services	Multidisciplinary home visiting for direct patient care, coordination, coun- selling, patient education, hereave- ment followup	Home visiting for direct patient care counselling, patient education, hereave- ment followup	Home visiting nursing for direct patient care, coun- selling, patient education hereavement followup	Counselling, patient education, hereave ment followup
Membership	1 M.D. Medical Advisor 2 Administrators 3 Coordinator/ supervisors 32 Coordinators 3 Social Workers 7 O. T.s 7 P.T.s 1 Nutritionist 2 Speech Therapists For entire programme, unable to quantitate time spent on pall- iative care	35 R.N.s ( 4 B.Sc.N, 1 B.A., 30 R.N.) 25 volunteers For entire programme, unable to quantitate time spent on pall- iative care	1 District Director 1 Assistant Director 3 Nursing Supervisors 36 R.N.s ( 15 B.Sc.N., 21 R.N.) Palliative Care Team 10 R.N.s ( 3B.Sc.N., 7 R.N. ) Friendly visitors	82 B.Sc.N or Dip. P.H. 1.5 R.N.A. 2 M.Sc.N. 2 M.H.Sc. For entire programme, unable to quantitate time spent on palliative care

Items	Home Care	St Elizabeth's	V.O.N.	Public Health
Funding Source	Ministry of Health	Home Care-99%, Regional Social Services, Donations, Investment Income	Home Care-95%, V.O.N. Investment Income, Donations. Regional Social Services	Hamilton-Wentworth Region 25%, Ministry of Health 75%. Home Care Programme revenue goes to Region
Duration Of Funding	Ongoing-budgets sub- ject to annual review	Ongoing-budgets sub- ject to annual review	Home Care cost/visit ongoing, Investment Income assured for 1 year specific to PCT	Ongoing-budgets subject to annual review
Per Diem Cost per Patient to Agency	\$ 10.64 (1981-1982) All costs/pt days for all patients,no costs stats for palliative care	\$ 24/visit (1983) Overall programme costs, suspect that palliative care would be more costly	\$ 1.38/visit -\$ 64.14/ day depending on # of visits (1982)	\$ 23.71/visit (1983) Cost for all patients- no specific stats for palliative care costs
Cost to Client	No direct cost to client for Home Care services. Patient may need to pay for shift nursing etc in addition to these services	No direct cost to client if eligible for Home Care or R.S.S. if not full or partial fee to patient or family	No direct cost to client if eligible for Home Care or R.S.S.,if not full or partial fee to patient or family	No direct cost to client
Average # of Care Hours/ Visits	Variable according to patient's and family's needs, not calculated specifically for palliative patients. Time for palliative patients is usually higher than non-palliative care patients. Additional visits may be negotiable as need arises. Range: biweekly to 2/day	Range: biweekly to 2/day	Range biweekly to 2/day	1/day - referred to other agencies if need is greater
Staff Support	Conferences weekly Supervisors, S.W. Medical advisor	Weekly team meetings, Supervisors,team leaders, peer support	Weekly team meetings supervisors, peer reviews monthly, nurse consultant, team leader. PCT team as consultants	Weekly District team meetings, supervisors, peer consultation,F.P. palliative & B.F. hi- weekly meetings, inter- agency consultation
There is also an informal interface between community agencies and institutions that provides support.				



Items	Home Care	St Elizabeth's	V.O.N.	Public Health
Expansion/ Reduction	No plans	As needs dictate	To be evaluated	For bereavement follow-up
Educational	1/2 day seminars Palliative Care Manual, CME day Academy of F.P. Private Duty nurses Funeral directors, Visiting homemakers presented. Opportunity for on- going education	Inservice for private duty agencies, 7 part series on palliative care for own nurses; Opportunity to attend educational events at outside agencies -CME presented.	PCT - formal orient- ation - 13 sessions, monthly inservice- 1.5 hrs., monthly oncology interest group meetings 1.5 hrs. Oncology Course at MUMC - 3 team members Charge nurse - as above + RVH - 1 week workshop + 1 week practicum + workshops - 7 days + seminars - 3 hours Also presented approx. 4 hrs education	Workshop, seminar attendance, professional development days for all days staff, professional reading
Research	None specific to palliative care	None specific to palliative care	Evaluation of Team in research format	None specific to palliative care
Evaluation of Present Services	As above	As above	As above + PCT team leaders reviews each case management, peer review bi-monthly to monthly for 1 hr., + joint consultations	None specific to palliative care
Access to Hosp- ital Bed: for G.P.	ER - risk of a long wait or of being sent home - few planned admissions - usually a waiting list for direct admission - not always available for short term pain control			Negotiated directly with specific physician and in- patient unit

TABLE 3, continued

Items	Home Care	St Elizabeth's	V.O.N.	Public Health
ELIGIBILITY; INCLUSION AND EXCLUSION CRITERIA				
Diagnosis	Medical referral required for admission to programme based on functional status Any end-stage illness - metastatic Ca., heart, renal, respiratory, neuromuscular			
Prognosis:	Variable depending upon diagnosis			
Age	All age groups	All age groups	Any age, range 1.5-96yrs	All age groups
Sex	Either	Either	Either	Either
Referral Source	Inquiry from any source, confirmed with attending physician	Primarily Home Care Regional Social Services, Cancer Society	Patients, family, friends, M.D.s, P.H.N.s Home Care, Cancer Society	Hospital health professionals, F.P.s, patients, family, clergy, etc.
Language & Cultural Barriers	Some difficulty finding interpreters			
Geog. Area Served	H-W region + referrals to other HC units	H-W region	H-W region	H-W region
Access to move Cure-Care	No exclusion Some difficulty with communication of treatments and results between acute centres especially Ca. Clinic and community agencies. Transportation by ambulance often involves long waits. Sometimes a difficulty obtaining consults re new symptomology. Weekend on-call physicians often do not know the case and are not informed re plan of care.	No exclusion	No exclusion	No exclusion

Items	Home Care	St Elizabeth's	V.O.N.	Public Health
UTILIZATION				
Programme Capacity	Unlimited at present- dependent upon needs of patients and families			No specific stats for palliative care
Coverage	Coordinators - 8:30-4:30 + 24 hr on-call coordinators	24 hr/7 days/week	24 hr/7 days/week	24 hr on-call
Admissions 81-82	No accurate stats specific to palliative care	For PCT average/wk- 60 One weeks stats- 27 under 65 yrs 33 - 65 yrs 24 - male 36 - female 172 visits/week		No stats specific to palliative care
Average length of stay	Range: Several weeks to years		Range: 3hrs-7mons.	No stats specific to palliative care
Referrals to Service	Hospital, M.D.s, P.H., Cancer Society			
Referrals from Service	Cancer Clinic, other Home Care programmes, F.P.s, private nursing agencies, Cancer Society, Regional Social Services, clergy, Coping with Cancer, Red Cross			
Discharge/Death	No stats specific to palliative care	128		No stats specific to palliative care

5. Palliative Care Services Provided by Private Duty Nursing Agencies

Table 4 demonstrates the comparability of palliative care services provided by five private duty nursing agencies in the Hamilton area on the variables: description of the programme, eligibility criteria and utilization of services.

The five agencies are fairly homogenous in the services they provide, the type of personnel available, eligibility criteria and utilization of services.

There are minor differences in the cost to client among the agencies for each of the categories of personnel. Two agencies (Community Nursing Registry, Comcare) are planning the development of palliative care teams in 1983.

Only Para-Med Health Services had statistics specific to palliative care available.

6. Bereavement Follow-up Programmes

Although all the agencies/institutions inventoried provide bereavement follow-up, with some programmes more formalized than others, there are two agencies providing this service specifically. The comparability of the two services on the variables: description of service, eligibility criteria and utilization of services is demonstrated in Table 5.

The Public Health Nursing Services of the Hamilton-Wentworth Regional Health Unit and the Family Services of Hamilton-Wentworth, Inc. both provide bereavement follow-up services.

There are a number of differences between the two services. Public Health Nursing has formed a Bereavement Follow-up Team of seven nurses prepared at the baccalaureate level. Family Services utilizes social workers to provide counselling.

Funding sources and cost to client also differ. There is no direct cost to client for the Public Health Service whereas Family Services has a counselling fee of forty-six dollars per hour which may be subsidized depending upon the client's ability to pay. They have also provided group counselling for parents following perinatal bereavement.

The Public Health Bereavement Follow-up Programme, which is at present mainly receiving referrals from St. Joseph's Hospital, is planning expansion of their services to other hospitals and community agencies in the area. They are hoping to include follow-ups on families experiencing trauma deaths, emergency room deaths and medical-surgical deaths as well as palliative and perinatal deaths. Family Services has no plans for expansion at the present time.

Educational input varied between the two services with the Public Health nurses having a more formalized programme at present.

7. Palliative Care Services Provided by Community Support Agencies

Two community support agencies are providing services to palliative care patients. The services are summarized in Table 6.

Both the Canadian Cancer Society and the Friendly Visitors provide volunteer services for palliative care patients and families. In addition, the Cancer Society provides funding for nursing and homemaking services as well as for dressings and equipment.

Funding sources differ with the Cancer Society's coming from their annual campaign while Friendly Visitors come from several sources.

TABLE 4

## Summary of Private Duty Nursing Agencies' Palliative Care Services

Items	Community Nsg Registry	Upjohn	Medical Personnel Pool	Para-med Health Services	Comcare
DESCRIPTION OF PROGRAMME					
Membership	R.N.	R.N. - 25 R.N.A. - 15	R.N., R.N.A. H. C. A.	R.N., R.N.A. H.C.A.	R.N., R.N.A. H.C.A.
Funding Source	Nurses bill directly	Direct - 50%	Direct - 50%	Direct billing	Direct billing
Duration Of Funding	Ongoing	Ongoing	Ongoing	Ongoing	Ongoing
Per Diem Cost per Patient to Agency	Unknown	Unknown	Unknown	Unknown	Unknown
Cost to Client	R.N.-\$105/8hr R.N.A.-\$9.60/hr	R.N.-\$12.65/hr R.N.A.-\$10.25/hr	R.N.-\$14.75/hr R.N.A.-\$10.25/hr	R.N.-\$13.25/hr. R.N.A.-\$8.50/hr H.C.A.-\$6.20/hr	Under review
Average # of	Variable according to patient's and family's needs				
Care Hours	24 hr	16 hr	16 hr	8-16hr/day	16 hr
Staff Support	None	Supervisors	Supervisors	None	None
Expansion/ Reduction	PC Team	No plans	Own supply of equipment	Willing to take on more PC patients	



Items	Community Nsg Registry	Upjohn	Medical Personnel Pool	Para-med Health Services	Comcare
Educational Function	Inservice all fall	Inservice Sept-Dec	Inservices	Inservice	None
Research	None	None	None	None	None
Access to Hosp- ital Beds for O.P.	ER	ER	ER	ER	
ELIGIBILITY; INCLUSION AND EXCLUSION CRITERIA					
Diagnosis	Any diagnosis - mainly Ca				
Prognosis	Variable depending on diagnosis				
Age	Any age -mainly adults but an increasing number of paediatric patients				
Sex	Either	Either	Either	Either	Either
Referral Source	Any	Any	Any	Any	Any
Language & Cultural Barriers	Some difficulty finding interpreters				
Geog. Area Served	H-W region + Halton, Grimsby To Hwy.10	H-W region Halton	H-w region To Hwy. 10	H-W region	H-W region
Access to move- Care	No exclusion Some difficulty with communication of treatments and results between acute centres and community agencies. Transportation by ambulance often involves long waits	No exclusion	No exclusion	N/A	

TABLE 4, continued

Items	Community Nsg Registry	Upjohn	Medical Personnel Pool	Para-med Health Services	Comcare
UTILIZATION					
Programme Capacity	Unknown - dependent upon needs of patients and families				
Coverage	24 hr/7days/week	24 hr/7days/week	24 hr/7days/week	24 hr/7days/week	
Admissions 81-82	No stats	No stats	No stats	16 between July & December 1982	No stats
Average length of stay	4 weeks	3 weeks	2 weeks	4 weeks	3 weeks
Referrals to Service	M.D.s, P.H., Cancer Society, Home Care, Patients and Families				
Referrals from Service	Cancer Society, Home Care, Public Health, clergy, Coping with Cancer, Red Cross, Regional Social Services				
Discharge/ Death	No stats - mostly deaths and some readmissions to hospital			16 deaths	

TABLE 5

## Summary of Bereavement Follow-up Services

Items	Public Health	Family Services
DESCRIPTION OF PROGRAMME		
Membership	R.N.	S.W.
Funding Source	Ministry Funding	United Way, Client Fees Regional Social Services
Duration Of Funding	Ongoing	Ongoing
Per Diem Cost per Patient to Agency	Unknown	Unknown
Cost to Client	\$ 0	\$ 46.00/hr but may be subsidized
Average # of Care Hours	Variable according to patient's and family's needs	
Staff Support	Conferences	Supervisors
Expansion/ Reduction	To other hospitals	No plans
Educational Function	Team learning	None

Items	Public Health	Family Services
Research	None	None
Access to Hospital Beds for O.P.	Through Family practitioners	
ELIGIBILITY; INCLUSION AND EXCLUSION CRITERIA		
Diagnosis	Any diagnosis - mainly Ca	
Prognosis	Variable depending on diagnosis	
Age	Any age	Any age
Sex	Either	Either
Referral Source	Mainly St Joseph's	Any
Language & Cultural Barriers	Some difficulty finding interpreters	
Geog. Area Served	H-W region	H-W region
Access to move	No exclusion	No exclusion

Items	Public Health	Family Services
UTILIZATION		
Programme Capacity	Unknown - dependent upon needs of patients and families	
Coverage	24 hr/7days/week on-call	24 hr/7days/week on-call
Admissions 81-82	No stats	No stats
Average length of stay	2-3 months	Unknown
Referrals to Service	Mainly St Joseph's	Clients, S.W.
Referrals from Service	Family Practitioners	
Discharge/Death	No stats	No stats

Table 6

Summary of Palliative Care Services Provided by  
Community Support Agencies

Items	Cancer Society	Friendly Visitors
DESCRIPTION OF PROGRAMME		
Services	Home visiting by volunteers, nursing and homemaking services, dressings & equipment	Home visiting by volunteers
Membership	Volunteers	Volunteers 40-50
Funding Source	Cancer Society Campaign	Cancer Society, United Way, V.O.N. grant, Regional,
Duration Of Funding	Ongoing	Ongoing
Per Diem Cost per Patient to Agency	Unknown	Unknown
Cost to Client	No direct cost	No direct cost
Average # of Care Hours	Variable according to patient's and family's needs; 336 nursing hours available; 224 housekeeping hours	Unknown
Staff Support	None	Team conferences with V.O.N. supervisors, P.C. nurses
Expansion/Reduction	Asking the national council to increase # of nursing hours	Increase in # of volunteers



TABLE 6, continued

Items	Cancer Society	Friendly Visitors
Educational Function	Public education	Inservice for all volunteers
Research	None	None
Access to Hospital Beds for O.P.	N/A	N/A
ELIGIBILITY; INCLUSION AND EXCLUSION CRITERIA		
Diagnosis	Cancer	Any
Prognosis	Variable depending on need	
Age	Any age	Any age
Sex	Either	Either
Referral Source	Any	Program offered only to Home Care Program clients
Language & Cultural Barriers	Some difficulty finding interpreters	
Geog. Area Served	H-W region	H-W region
Access to move	N/A	N/A
UTILIZATION		
Programme Capacity	Unknown - dependent upon needs of patients and families	
Coverage	24 hr/7days/week on-call	24 hr/7days/week on-call

TABLE 6, continued

Items	Cancer Society	Friendly Visitors
Admissions 81-82	No stats	23 patients
Average length of stay	10-15 days	Unknown
Referrals to Service	Home Care, Private Duty Agencies, M.D., Hospitals	Home Care, V.O.N. P.H.N.
Referrals from Service	Home Care, P.H., Family Services, Bereaved Parents Widow to Widow, March of Dimes Princess Margaret	
Discharge/ Death	No stats	No stats

8. Palliative Care in Nursing Homes

In November of 1982, the Palliative Care Task Force sent out 21 preliminary questionnaires to nursing homes in the district. There were 9 responses returned. Of these, 4 refused to be interviewed. Five directors of nursing were interviewed. Because of the low number of responses and the fact that all but one of these were small homes, three additional, large nursing homes - St. Elizabeth's, Downtown Convalescent and Mountain Nursing Homes, as well as three homes for the aged - St. Joseph's Villa, Macassa Lodge and Wentworth Lodge were interviewed. All responded. Because of the limited number of responses, data obtained must be viewed with caution.

Most respondees had difficulty defining the separation between chronic or long term care and palliative care. The smaller homes send most patients to acute care facilities to die for two main reasons. The first is the lack of equipment, eg., oxygen to make the patient comfortable during the terminal stages. The second is the fact that deaths in nursing homes automatically become cases for investigation by the coroner's office. The larger homes will maintain the patient in the facility if the patient or family request it and the attending physician agrees. However, problems can arise if there is a disagreement between family and physician as to where the patient should die.

The number of deaths in nursing homes and homes for the aged ranges from 2-3 per month to 1-2 per year.

The responses indicate a low level of knowledge concerning the resources for palliative care patients within the community. Educational activities mainly are those sought by individual staff members beyond the work environment. One institution has held two inservice educational sessions on palliative care for its staff and another institution is starting a series of inservices on palliative care in June, 1983. Two of eleven respondees utilize Home Care consultations for their palliative care patients, eg., physiotherapist or occupational therapist.

Family support through the terminal stages is minimal and done on an individual basis. Bereavement follow-up is done on an informal basis by the staff on their own time. Little or no support is given to the remaining residents when a death occurs. No formal methods of staff support exist. Staff support is given on an incidental basis, if at all.

Although the survey number was small, the identified needs are similar to those put forth by other institutions and agencies within the community.

9. Hamilton and District Funeral Service Association

The funeral directors in their brief identified three main areas where they may provide service for palliative care patients and their families.

A major area of concern for the funeral directors was bereavement follow-up with the immediate family. Since they are involved with the family at the time immediately following death, the funeral directors may be a source of referral for a bereavement follow-up programme, especially for families with minimal or no involvement with health care agencies.

Secondly, if the patient and/or family wished to talk with each other about death and funerals or plan around these issues, funeral directors would be available for conferences in the home or hospital.

The third area where funeral directors felt they could be of assistance was in the interaction between professional groups. They are willing to act as educational and supportive resources for health care professionals, thereby benefiting palliative care patients and their families.

10. Hamilton and District Christian Churches Association

In their brief, the Christian Churches Association described the services that the clergy provide for palliative care patients and their families.

In general, the parish priest/minister is the focal point for care, supported by a group of volunteers. Almost all denominations have employed hospital chaplains to care for people who are from out-of-town, or who are unaffiliated with a particular congregation.

Palliative care involves understanding and supporting the patient, family and friends through the terminal stages and following death. Formal bereavement care includes an immediate visit to the bereaved, funeral planning and follow-up visits. These visits vary in intensity and frequency depending upon the circumstances. Referral for counselling or therapy from health care professionals may occur.

Parish clergy do not usually see themselves as part of the team approach to the needs of the dying in the hospital and only occasionally in home care or nursing home care.

Attempts at "training for visitation" which include issues in death and dying are very ad hoc and not enthusiastically attended. There have been congregational study groups on death and dying. There is a general lack of consistency in screening and training of volunteers for palliative care.

11. Palliative Care Education

Representatives of educational institutions in the region were approached to ascertain the quantity of palliative care education offered both on the undergraduate and postgraduate levels for health care professionals.

a) Undergraduate Education

In view of the types of learning utilized in medical and nursing undergraduate programmes in Hamilton, it is very difficult to estimate for any programme the amount of time allotted to the care of the dying.

The medical and nursing programmes at McMaster University utilize the Problem-Based Learning Methodology. This means that, although all students are exposed to concepts surrounding death and care of the dying, the depth of knowledge attained and the clinical experience obtained in this area are very individualized.

The Mohawk College Diploma Nursing Programme utilizes learning by objectives and is based on the Roy Adaptation Model. The concepts of death and dying are carried as a "thread" throughout the modules upon which the programme is based. Again, it is difficult to estimate the amount of time spent as the depth of knowledge and clinical experience are also individualized in this programme.

b) Postgraduate Education

The opportunity exists in both the Post-R.N. Degree Programme and the Masters of Health Science (Health Care Practice) Programme for the students to select an elective in palliative care depending upon the availability of clinical facilities and faculty supervision.

The quantity of palliative care education in the medical residency programmes is also very individualized depending upon the core programmes selected, the clinical placements and the faculty supervision available.

c) Continuing Education

McMaster University offered two educational events in palliative care in 1982. The Programme in Continuing Medical Education offered a Day in Palliative Care in May, 1982 which 126 health professionals attended.



The Postgraduate Academic Studies Programme offered a six-week course, "Philosophy and Techniques of Palliative Care", from October 18 to November 22, 1982. Seventy-six health professionals applied and thirty-seven were accepted. There is a waiting list of thirty for the next course offering.

The Hamilton Academy of Medicine offered two presentations concerning palliative care in recent months. "Palliative Care in the Home" was offered in November, 1982; "The Management of Severe Cancer Pain in the Home Setting" in January, 1983. Both were attended by approximately fifty members.

The Clinical Behavioral Sciences Programme, although it has not identified practitioners with an interest in palliative care, offers courses that would increase the knowledge and skill levels of health professionals involved in palliative care. Although the programme advocates the integration of practitioners from various backgrounds in its courses, consideration would be given to a stream for professionals involved in palliative care if the need was identified within the community.

Mohawk College, in keeping with its policy of avoiding duplication of programmes offered by McMaster University, has not developed any palliative care education courses.

d) Summary

In addition to these activities, there have been a number of inservice programmes and seminars at the various institutions and agencies in the community as well as events for interested community groups such as service clubs, church groups and paramedics. These are enumerated in the institution and agency inventories.

12. Perceived Needs and Gaps in Palliative Care Services

Needs and gaps in palliative care services were identified by all key informants in the inventory as well as by the Hamilton and District Funeral Service Association and the Hamilton and District Christian Churches Association. These are delineated in Table 7 as are the proportions of the respondents. The Health Professions Coordination Group "A" of the District Health Council also identified a number of concerns in this area (see Appendix VII).

In addition, the survey of family practitioners identified many issues. Since there was no significant difference in the results between the two types of practitioners - group or solo, the data was summarized together. The identified needs and gaps as well as the proportions of the total for each response are displayed in Table 8.

Similar concerns issued from all sectors of caregivers surveyed. The responses fell into five main categories: (1) financial issues, (2) communication difficulties, (3) difficulties in coordination, (4) need for education, and (5) services needed. There was obviously some overlap between the categories, with some issues being addressed in more than one category. Responses varied from general concerns to specific suggestions for travelling records and regional assessment forms for palliative care patients. Responses, number of responses per group surveyed and totals are summarized in Table 9.

13. Duplication of Services

Three main areas of duplication of services were identified in the survey. The first is the overlapping of role functions between different categories of professionals. The second is the repetition of patient assessment by a number of persons, mainly because information is not communicated quickly enough - eg., hospital team and home care nurse or public health nurse are both doing assessments.

The third duplication is in the area of bereavement follow-up. Since bereavement follow-up is mainly being done on an informal basis with no one person or agency being identified as responsible, several persons or none may be involved in follow-up. There is some territoriality existing with groups not wishing to turn patients they have been involved with over a long period of time over to another group for bereavement follow-up.

#### 14. Demographic Data

In considering the potential target population for palliative care in Hamilton-Wentworth, several areas must be examined.

##### a) Population

In 1981, Hamilton-Wentworth had a resident population of 411,445, approximately 75% of which resided in the City of Hamilton. Approximately 136,000 persons (32.8%) fell in the 45+ years age groups; the age groups in which 92.5% of the deaths from neoplasms occurred.

The significant trends in resident population are a decrease in the youth and young adult population and an increase in the mature adult (35-64 years) and senior citizen (64+ years) groups.

##### b) Morbidity/Mortality

The number of new cancer cases registered at the Hamilton Cancer Clinic increased from 1487 in 1971 to 2507 in 1980 - an increase of approximately 60%. In 1980, over 50% of these new cases listed Hamilton-Wentworth as their place of residence.

In Ontario, the death rate appears to be slowly decreasing since 1970, whereas, in Hamilton-Wentworth the trend is to an increasing number of deaths (Appendix IX).

Appendix IX also contains cancer incidence tables, total deaths in Hamilton-Wentworth and in Ontario, deaths by age groups and by hospitals in the region as well as Home Care deaths.

The data in this Appendix demonstrate:

- 1) That approximately 90% of deaths from neoplastic disease occur in hospital in Hamilton-Wentworth.
- 2) That approximately 45% of the deaths from neoplastic disease occur at the Henderson General Hospital and 25% occur at St. Joseph's Hospital.
- 3) That the number of deaths from neoplasms at the McMaster University Medical Centre doubled from 1979 to 1982.

\* \* \* \* \*

In summary, this chapter delineates the palliative care services available in the region. As well, the perceived unmet needs and gaps in service and the duplications in service are displayed and summarized in Table 9. These were used along with the information obtained from the literature review in determining the recommendations included in Chapter 4 of this report.

TABLE 7

Summary of Data from Palliative Care Inventory\*  
Re: Unmet Needs and Gaps in Service

Perceived Needs and Gaps in Service	Proportion of Respondents
1. Financial:	
- financial support for families of patients dying at home for:	
i) nursing care when insurances and Cancer Society hours run out and criteria for Regional Social Services can't be met	7/21
ii) palliative care services for terminal patients with non-malignant diseases	9/21
iii) for equipment and dressings etc. when not covered by Home Care, Cancer Society or insurances	4/21
- coverage for services for patients who are allowed out of hospital on day passes but need nursing services while at home - eg. dressing change, Hickman catheter flush	2/21
- need for private insurance coverage to extend beyond R.N. category to R.N.A. and Homemaker as R.N. usage is not always appropriate	11/21
- expansion of some services in the home - eg. the number of visits allowed for pain injections per day	2/21
- funding for bereavement follow-up	14/21
- conditional funding for welfare funerals to be arranged in advance	1/21
- need for economical funerals	1/21
2. Communication:	
- a need for improved communication between agencies and individuals involved in patient care. The lag	

TABLE 7, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
time between patient's arrival for care and information arrival is often high (2-3 days). Establishing telephone contact is often difficult and time consuming, producing a need for duplication of service - eg. assessment of needs	13/21
- a need to indentify to patient, family and all members of the team who is primary case manager for each patient	5/21
- a need for communication aids:	
i) regional travelling record for the patient	6/21
ii) palliative care communication record including assessment of needs and interventions to be forwarded immediately between agencies and individuals involved in patient care when any transfer between services is made. A copy should always be forwarded to the family practitioner immediately	10/21
iii) regional pain assessment and evaluation forms	1/21
iv) regional medication charting sheet for home patients	1/21
v) an information, self-help book for patients dying at home	4/21
3. Coordination:	
- a need for continuity of care for the patient and the family with coordination between all agencies and no gaps to hinder total care	11/21
- a acceptable definition of palliative care for the region	5/21



TABLE 7, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
- establishment of acceptable standards of palliative care for the region	2/21
- a regional palliative care coordinator to:	
i) act as a resource for all community agencies	
ii) to establish educational needs in palliative care and coordinate educational programmes	
iii) to identify and coordinate research in the region	
iv) to coordinate services in the community	6/21
- availability of a 24 hour per day telephone resource for patients and family	4/21
- availability of consultation house calls with family practitioners	1/21
- an inventory or directory of services available for palliative care patients	8/21
- coordination of volunteers regionally for:	
i) service	
ii) education	3/21
- coordination and sharing between hospital teams	2/21
- an organized system by which ambulances will return patients to the facility where their records and primary health team is located	3/21

TABLE 7, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
-------------------------------------	---------------------------

4. Education

1) Public Education

- education around grief and death including:

- |   |      |
|---|------|
| i) the right to be assertive about needs  |      |
| ii) the right to seek another opinion<br>or to refuse treatment and not<br>be abandoned |      |
| iii) availability of symptom control  |      |
| iv) option of where to die and associated<br>advantages and disadvantages               | 8/21 |
| - education around resources - insurances<br>- community agencies                       | 6/21 |
| - education in schools for teachers<br>around grief and death                           | 3/21 |

2) Professional Education

- |  |       |
|--|-------|
| - education needed for all catagories of<br>professionals as well as for volunteers<br>working in palliative care including: |       |
| i) working through their own feelings<br>and attitudes about grief and daeth   |       |
| ii) interviewing skills  |       |
| iii) pain management   |       |
| iv) symptom control  | 16/21 |
| v) nutritional aspects   | 3/21  |
| vi) stress and staff support   | 4/21  |
| vii) availability of community resources   | 7/21  |
| viii) the need for continuity of care<br>and flexibility of services   | 1/21  |

TABLE 7, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
-------------------------------------	---------------------------

- |  |      |
|--|------|
| ix) the need for a multidisciplinary team and the designation of a care coordinator for each patient - may be patient, family or any team member depending on individual circumstances and needs | 5/21 |
| x) the need for bereavement follow-up  | 5/21 |
| - education in palliative care now needs to increase depth and scope of content areas beyond an awareness level into developing specific skills  | 2/21 |
| - regional palliative care rounds  | 1/21 |

#### 5. Services:

- bereavement follow-up including:
    - i) a formalized system for follow-up of identified high risk individuals and families
    - ii) criteria for assessment of high risk individuals and an assessment tool for follow-up
    - iii) funding beyond existing monies
    - iv) education of professionals and laity regarding need and resources for bereavement follow-up
- |  |       |
|--|-------|
|  | 17/21 |
|--|-------|
- a palliative care unit of a limited number of beds to accomodate persons whose community services have run out; who cannot for physical or psycho-social reasons be managed at home
- |  |      |
|--|------|
|  | 6/21 |
|--|------|
- increased support services for caregivers in family. Concerns of professionals for this group resolve around such issues as:

TABLE 7, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
i) loss of income	
ii) change of roles	
iii) guilt surrounding patient care, possible rehospitalization and/or home care if hospitalized	5/21
iv) need for respite care	3/21
v) increased morbidity and risk of mortality among caregivers	5/21
vi) depletion of family resources to maintain patient at home	5/21
- more organized support for health care team - counselling services, organized peer support	4/21
- job and financial counselling for widows	4/21
- improved ambulance service for patients going by ambulance for assessment or palliative treatment. There are often long waiting periods for these patients	4/21
- improved services at the time of death in the home:	
i) education re use of 911 calls	
ii) importance of an M.D. being available to pronounce death for a patient dying at home	
iii) improved body removal services	6/21
- regional research programmes into palliative care	7/21
- funeral services for people with minimal denominational affiliation	1/21

\* Includes responses from hospitals, home health care agencies, private duty agencies, community support services, Funeral Directors Association & Christian Churches Association

\*\* Input from Hamilton and District Funeral Association was considered as one response as was input from Hamilton and District Christian Churches Association

TABLE 8

Summary of Data from Survey of Family Practitioners  
Re: Unmet Needs and Gaps in Palliative Care Services

Perceived Needs and Gaps in Service	Proportion of Respondents
1. Financial: 40 of 59 respondents answered this question; 13 indicated satisfactory services; 27 indicated unmet needs or gaps	
- financial support should be a fiscal priority	8/59
- financial assistance for round the clock nursing in the home, if necessary	14/59
- financial support for part or full-time housekeeping services	7/59
- lack of funding for palliative care staff for all hospitals	3/59
- funding methods other than fee-for-service for M.D.s involved in palliative care	1/59
- financial assistance for equipment and supplies	6/59
- insurance funding for personnel other than R.N.	2/59
- help for patients who are not landed immigrants	1/59
- funding for hospices	1/59
- support from charitable organizations	3/59
- questions the cost-effectiveness of palliative care	1/59
2. Communication: 52 Of 59 responded to this question; 22 indicated services were satisfactory; 30 indicated unmet needs and gaps.	
- a chart or record to be kept with the patient for all health care providers to make entries on the progress notes	2/59

TABLE 8, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
- lack of communication with the family physician re changes in the patient's management	14/59
- method of coordination of communication between agencies	8/59
- involvement of family physician in team conferences	2/59
- one person should coordinate care and all others communicate directly with that person	7/59
- communication with the Cancer Clinic difficult - more knowledge concerning patient management needs to be communicated to the family practitioner	8/59
- should be under the direction of the family physician	2/59
3. Coordination: 47 of 59 respondents replied to the question; 23 indicated satisfactory services; 24 indicated unmet needs or gaps.	
- more use of the V.O.N., P.H.N. and Home Care in coordination	2/59
- one person appointed to coordinate care for each patient and family	14/59
- coordinating body for all palliative care	1/59
- conferences at home or in hospital involving all groups involved in patient care, including patient and family	4/59
- remuneration for family practitioners involved in coordinating activities other than fee-for-service	1/59
- should be under the direction of family physician	3/59



TABLE 8, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
4. Education: 43 of 59 respondents replied to the question; 6 indicated satisfactory services; 37 indicated unmet needs or gaps.	
- of public, regarding services and resources available	21/59
- of health professionals, regarding resources and services available	26/59
- lack of professional training opportunities in palliative care	4/59
- of patients and relatives as to the expected goals of palliative care	3/59
- education of nurses from private duty agencies around palliative care issues	1/59
- education of patients and families re unproven treatment modalities - eg. megavitamins, Essiac, Laetrile; including the risks, costs etc.	1/59
5. Services: 39 of 59 respondents replied to this question; 15 indicated satisfactory services; 23 indicated unmet needs and gaps and 1 indicated a need for reduction in services.	
- an increase in present services as more patients elect to die at home	15/59
- a palliative care team at the Hamilton General Hospital	1/59
- regular visits by the family physician without having to be called	1/59
- palliative care beds	4/59
- easier placement in chronic hospitals when needed	2/59
- telephone monitoring service for palliative care patients - possibly volunteer	2/59
- increased pharmacy services for patients needing analgesics	1/59

TABLE 8, continued

Perceived Needs and Gaps in Service	Proportion of Respondents
- consultations for family physicians in the home	3/59
- an increase in staffing for hospital teams	3/59
- an increase in services with respect to emotional and social needs of the patient and family	5/59
6. Other Needs/Gaps: 22 Of 59 responded to this question; 4 indicated satisfactory services; 18 indicated unmet needs or gaps.	
- transportation to and from tertiary care facilities, M.D.s offices etc.	2/59
- access to hospital beds on short notice	5/59
- research: 1) to determine need 2) randomized clinical trial to determine if services made any difference	4/59
- more involvement of the clergy in meeting the spiritual needs of the patient both in hospital and in the home	1/59
- development of volunteer services	3/59
- outreach programmes in the community for palliative care patients and their families	1/59
- bereavement counselling for next of kin/surviving relatives	2/59
- support system for health care workers dealing with a highly emotional problem	1/59
- hospice facilities as in the United Kingdom	1/59

TABLE 9

Summary of All Perceived Needs and Gaps  
in Palliative Care from Key Informants

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
1) Financial:					
- financial support for patients dying at home and their families	13	13	--	1	27
- coverage for ser- vices for patients who are allowed out of hospital on day passes but need nursing services at home	2	--	--	--	2
- need to extend in- surance coverage be- yond RN category to RNA and Homemaker	11	2	--	--	13
- expansion of some services in the home - # of nursing visits, equipment provision, homemaking	2	12	--	1	15
- funding for hereave- ment follow-up	14	--	5	1	20
- conditional funding for welfare funerals to be arranged in advance	1	--	--	--	1
- financial support for p.c. should be fiscal priority	--	7	--	--	7
- lack of funding for p.c. staff for all hospitals	1	5	--	--	6
- funding methods other than fee-for- service for M.D.s involved in p.c.	--	2	--	--	2

TABLE 9, continued

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
- help for patients who are not landed immigrants	--	1	--	--	1
- funding for hospices	1	--	--	--	1
- support from charitable organizations eg, United Way	--	3	--	--	3
- determination of cost-effectiveness of palliative care	--	1	--	--	1
- need for economical funerals	1	--	--	--	1
2. Communication:					
- a need for improved communication between institutions, agencies & individuals involved in patient care	13	20	--	1	34
- a need to identify to patient, family & all caregivers who is primary case manager for each patient - all others communicate with case manager	5	7	--	1	13
- communication aids	11	2	--	1	14
- should be under the direction of the family practitioners	--	2	--	--	2
- communication with the Cancer Clinic is difficult - more knowledge re patient management needs to be communicated to family practitioner	4	8	--	--	12

TABLE 9, continued

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
3) Coordination					
- a need for continuity of care for the patient & family with coordination between all services and agencies	12	18	--	1	31
- an acceptable definition for p.c. for the region	5	--	--	--	5
- establishment of acceptable standards of p.c. for region	2	--	--	1	3
- regional p.c. coordinator	6	--	--	--	6
- availability of a 24 hr./day telephone resource for patients & families	4	2	--	--	6
- availability of consultation house-calls with family physician	1	3	--	--	4
- a directory of services available for p.c. patients	8	--	8	--	16
-coordination of volunteers regionally	3	3	3	1	10
- coordination and sharing between hospital teams	2	--	--	--	2
- organized system by which ambulances return patients to the facility where their records and primary health team is located	3	--	--	--	3
- appropriate referrals to various health team					

TABLE 9, continued

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
members at optimal time for service	--	--	--	1	1
- utilization of chiropractors in p.c. in institutions, & community	--	--	--	1	1
- identification in p.c. of a point of entry or method of extending services for various disciplines	--	--	--	1	1
-formalized committee for provision of information & coordination of available services	1	1	2	1	5
- conferences at home or in hospital involving all groups involved in care	--	4	--	--	4
-more use of Home Care, V.O.N., P.H.N. in coordination of care	--	2	--	--	2
- should be under the direction of family practitioner	--	3	--	--	3
4. Education:					
- public education re dying, death, grief & resources available for p.c. patients and their families	16	25	11	1	53
- education in schools for teachers & students around grief and death	3	--	--	--	3
- of health professionals in all catagories re philosophy & concepts of p.c.; dying, death and grief processes & services					



TABLE 9, continued

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
& resources available to them	18	30	11	1	60
- regional palliative care rounds	1	--	--	--	1
- lack of professional training opportunities in p.c.	--	4	--	--	4
5. Services:					
- a formalized bereavement follow-up system of identified high risk individuals or families ( service & education )	17	2	11	1	31
- palliative care unit of a limited # of beds to accommodate persons whose community services have run out; who cannot for physical or psychosocial reasons be managed at home	6	4	--	--	10
- palliative care team at Hamilton General Hospital	--	1	--	--	1
- Increased support for caregivers in family - financial, physical, emotional	8	20	--	--	28
- more organized support for health care team - counselling, peer support meetings	4	1	--	--	5
- job & financial counselling for widows	4	--	--	--	4
- improved ambulance service for patients going by ambulance for assessment or palliative treatment	4	--	--	--	4

TABLE 9, continued

Perceived Needs & Gaps	Inventory*	F.P. Survey	Nsg Home	Gp"A"	Total
- increased pharmacy services for patients requiring analgesics	--	1	--	--	1
-transportation services to and from tertiary care facilities, M.D.'s offices	--	1	--	--	1
- access to hospital beds on short notice	3	5	--	--	8
- hospice facilities as in the United Kingdom	--	1	--	--	1
- regular visits by family physician without being called	--	1	--	--	1
- regional research into palliative care	7	4	--	--	11

\* Includes input from hospitals, home health care agencies, private duty agencies, community support services, Funeral Director's Association, and Christian Churches Association.

\*\* Input from Health Professions Coordination Group "A" was considered as on response.

## Chapter IV

### CONCLUSIONS AND RECOMMENDATIONS

In order to develop the following recommendations, the Palliative Care Task Force examined the literature review concerning planning aspects of palliative care, the results of the inventory of key informants, the briefs submitted by community support groups, the perceived needs and gaps identified in our present palliative care services and the population data. This was done in light of the goals and objectives of the Task Force and the recommendations are aimed at providing solutions to the identified problems.

The following recommendations are organized in a format similar to the literature review. The Task Force also considered the relative importance of recommendations and prioritized them. The priority rank appears beside each recommendation, and the recommendations are listed in priority order in the Executive Summary.

#### 1. Definition of Palliative Care

In attempting to establish an acceptable definition of palliative care for the region, the Task Force considered both the components defined in the literature and the inventory of the agencies/institutions surveyed. It was felt that a definition which could be universally accepted throughout the region would provide a common basis for the development of eligibility criteria, standards of care and education. In addition, the collection of data, for evaluation of services and research, would be more comparable if it were based on the same definition.

Recommendation 1 (Priority #3):

THE TASK FORCE RECOMMENDS THAT THE FOLLOWING DEFINITION BE ACCEPTED FOR HAMILTON-WENTWORTH AND THAT THE DEFINITION BE DISSEMINATED TO ALL PROGRAMMES/INSTITUTIONS/AGENCIES PROVIDING SERVICE, EDUCATION OR RESEARCH IN THE AREA OF PALLIATIVE CARE.

Palliative Care:

Palliative care is the active, compassionate care of the sick at a time when the goals of cure and prolongation of life are no longer paramount. The emphasis is on control of symptoms, and physical, emotional and spiritual care. It is multi-disciplinary in its approach, encompassing the patient, the family and the community in its scope and extends to include the bereavement process.

2. Standards of Practice

The Task Force, in recommending the adoption of the standards of the International Work Group on Death, Dying and Bereavement (20) for our region, considered the scope of the standards and the flexibility inherent in them. The document includes patient-oriented, family-oriented and staff-oriented standards. Minimal attention is given to standards defining administrative roles and methods of provision of service. However, these could easily be developed more fully with input from other authors, eg., Salladay (25) and the guidelines set down by Health and Welfare Canada (12).

The second advantage to this document is that it presents assumptions and principles, not rigid standards. This will allow each institution/agency to develop specific standards and objectives within these broader principles, according to its own philosophy and resources.

The need for monitoring improved methods of delivering health care is well documented in the literature; as is the need for objectives and standards to be in place as criteria against which the quality of care can be measured. Salladay (25) states, "The process of hospice planning includes the following steps:....5. Establishing a review or evaluation process for ongoing performance vis-a-vis objectives and standards of the hospice. Each step of the process is critical". This is supported by Rossman (24) who says, "For good terminal care the delivery system must have a set of standards upon which to structure and evaluate its caring function. There is evidence that lack of agreed-upon standards contributes to the unacceptable level of care which is frequently observed." These standards must be incorporated into the practice of all institutions, agencies and individual clinicians including family practitioners who are involved in providing palliative care services. The monitoring of the level of care available must include all these service providers. The Task Force recognizes the difficulties involved in doing this in the community but emphasizes the importance of this monitoring especially in the community where standards of practice are more apt to be variable than in an institution.

In view of these facts and the fact that none of the programmes in Hamilton-Wentworth have a formalized set of standards in place, the Task Force recommends:

Recommendation 2 (Priority #4):

THE TASK FORCE RECOMMENDS THAT THE STANDARDS OF THE INTERNATIONAL WORK GROUP ON DEATH, DYING AND BEREAVEMENT BE ADOPTED FOR HAMILTON-WENTWORTH TO BE UTILIZED AS A BASIS FOR SPECIFIC STANDARDS AND OBJECTIVES TO BE DRAWN UP IN EACH SETTING INVOLVED WITH PALLIATIVE CARE SERVICES, EDUCATION OR RESEARCH.

These standards are attached in Appendix VIII.

Recommendation 3 (Priority #12):

THE TASK FORCE RECOMMENDS THAT A STRUCTURE FOR MONITORING THE IMPLEMENTATION OF STANDARDS FOR ALL PALLIATIVE CARE SERVICES PROVIDERS WITHIN INSTITUTIONS AND AGENCIES AND ESPECIALLY WITHIN THE COMMUNITY BE ESTABLISHED.

This could be done in the format of a research project in conjunction with the Department of Clinical Epidemiology and Biostatistics at McMaster University. The study would look at the effectiveness of the delivery of terminal care in the region based on established indices of good palliative care and utilizing audit tools as endorsed in Recommendation 14.

3. Models of Care

The various models of delivering palliative care have been set down in Chapter 2 of this document. As Scott (27) indicates, hospice care in the U.S.A. grew from home care teams in the direction of autonomous free-standing hospices, while the Canadian scene developed very differently. The Canadian pioneers were committed to the university teaching hospital and it has been in this setting that most developments have occurred. Canadians attempted to adopt the hospice model of the U.K. so that it fits within the structure of an active treatment hospital. Throughout Canada, the palliative care unit (PCU) is now being accepted as a special care unit within the acute care hospital with the same geographical and staffing autonomy required by an intensive care unit (ICU) or coronary care unit (CCU).

Scott also mentions that these special units and teams, "...are needed in each region, associated with the university teaching hospitals to serve as training, demonstration, consultation and research centres." In addition to these hospital-based teams and units, the importance of a palliative care team for the terminally ill at home is stressed in the literature (12, 13, 16). These three components - the consultation team, the integrated unit, and, the home care team - seem most feasible in this region.



The need for a core team of multi-disciplinary services has been well described in the literature. Lack (15) states, "It is vital to the psychological and physical well-being of the patient with a terminal illness that the physician is a key figure in the care received." and, "It is often the loss of their doctor's interest that patients fear most." Therefore, it is essential that the physician take a strong role in the palliative care core team and have a time commitment appropriate to fill that role. Lack also indicates that, "Medical direction of the (hospice) program was also vital in gaining acceptance by the medical community.".

Mount (22) defines the palliative care core team as consisting of physician, nurse, social worker, clergy, patient care coordinator and volunteer director in addition to the patient and the family and the attending physician.

Freedman (7) also supports the concept of a multi-disciplinary team. He identifies the importance of certain members of the team who promote successful functioning of the programme. These include the clinical nurse specialist, social worker, oncology nurse coordinator, physician and volunteers.

As recommended by several key informants, the primary case manager for each patient should be identified to the patient, family and all caregivers, so that all communication would be through this primary case manager.

A hospital-based team can provide services throughout its institution to all patients requiring palliative care and collaborate with home health care services to provide continuity of care and education in the community. A community-based team can provide services in the home, education in the community and establish a liaison with hospital teams to provide continuity of care.

The need for continuity of care is also delineated. Lack (15) indicates that, "Interdisciplinary care must not be synonymous with fragmented care in which the patient does not know who is in charge or who is dealing with which problem.".

The palliative care unit would be a designated geographic ward designed, equipped and staffed to care for the small group of dying patients with high symptom control needs whose care could not be managed in the community and to meet the needs of their families. The therapeutic environment would include policies which would facilitate visiting, and overnight stays by family members as well as direct telephone access to the medical team. In addition, it would include physical space for such things as lounges and a kitchenette for patients and their families, a "quiet room", offices for staff and conference rooms. Also included would be provision for adequate nursing care time to meet the needs of the patient and family.

A consultation team is already in place at St. Joseph's Hospital, Chedoke-McMaster Hospitals and Henderson General Hospital as described in the inventory data. The addition of a team at the Hamilton General Hospital and the upgrading of the other teams plus the establishment of hospital units would be a major step in meeting palliative care service and education needs in our region.

The necessity of ready access to hospital beds as needed for palliative care patients is also well documented. Health and Welfare Canada (12) states, "Experience suggests that the assurance of 'a bed when necessary' is reassuring to both patient and family, allays fears and enables the patient to be at home longer.". This view is supported by a number of authors such as Lack (15), Rossman (24) and Saunders (26). There is a need for such policies in this region as is documented in the inventory. At present, palliative care admissions have no priority and often entail long waits either at home or in emergency rooms.

The philosophy of palliative care incorporates the idea that the patient and family will have the choice of where the patient will die - in hospital or at home. Emphasis is on having the patient spend as much time as is appropriate in his own home. To be able to accomplish this, there must be provision of home care services by a group of health professionals with interest and expertise in palliative care. There must also be integration of the hospital palliative care services with the community home care services and other community resources to prevent gaps and/or duplication in services.

Some services suggested by the key informants, if implemented would more easily enable patients to stay in their homes longer. These services include the following:

1. financial support for patients dying at home
2. coverage for services for patients who are allowed out of hospital on day passes but need nursing services at home
3. improved communication between institutions, agencies and individuals involved in patient care
4. a 24-hour per day telephone resource for patients and families
5. consultation housecalls with family physicians
6. a directory of services available to palliative care patients
7. regional coordination of volunteers
8. more use of Home Care, Victorian Order of Nurses and Public Health Nursing in coordination of care
9. increased financial, physical and emotional support for caregivers in the family of the palliative care patient
10. transportation services to and from tertiary care facilities and physicians' offices.

Hamilton-Wentworth has, at present, a strong foundation for home palliative care with the Victorian Order of Nurses Palliative Care Team and the interest and expertise within the Home Care Programme, St. Elizabeth's and Public Health Nursing. These programmes should be supported and expanded to provide additional means of meeting gaps in palliative care services in the region.

Recommendation 4 (Priority #6):

THE TASK FORCE RECOMMENDS THAT ST. JOSEPH'S HOSPITAL AND HENDERSON GENERAL HOSPITAL ESTABLISH OR MAINTAIN FULLY DEVELOPED PALLIATIVE CARE CONSULTATION TEAMS IN THEIR INSTITUTIONS. IT ALSO RECOMMENDS THAT HAMILTON GENERAL HOSPITAL AND McMASTER UNIVERSITY MEDICAL CENTRE ESTABLISH OR MAINTAIN PALLIATIVE CARE CONSULTATION TEAMS TO INCLUDE AN APPROPRIATE AMOUNT OF PHYSICIAN, NURSING, SOCIAL WORK AND CHAPLAINCY SERVICES TO MEET THE NEEDS OF PALLIATIVE CARE PATIENTS IN THEIR INSTITUTIONS. THESE TEAMS SHOULD BE REVIEWED ON AN ONGOING BASIS TO ENSURE THAT THEIR STAFFING COMPLEMENT IS ADEQUATE TO MEET THE NEEDS OF THESE PATIENTS.

IN ADDITION, THE TASK FORCE ALSO RECOMMENDS THAT CHEDOKE HOSPITAL DIVISION AND ST. PETER'S CENTRE CONTINUE TO MONITOR THE NEED FOR PALLIATIVE CARE SERVICES IN THEIR INSTITUTIONS.

The Task Force agrees that a fully developed palliative care team includes at least a physician with a 50% time commitment, full time nurse, a full time social worker and sufficient chaplaincy services to meet the needs of patients and families. A clearly defined case manager for each patient is needed. An active home care liaison is essential to provide continuity of care.

Recommendation 5 (Priority #11):

THE TASK FORCE RECOMMENDS THE DESIGNATION OF A PALLIATIVE UNIT ENVIRONMENT WITH SUPPORTIVE STAFF IN ST. JOSEPH'S HOSPITAL, HAMILTON CIVIC HOSPITALS, INCLUDING THE HAMILTON GENERAL AND THE HENDERSON GENERAL, AND CHEDOKE-McMASTER HOSPITALS TO CARE FOR THE SMALL PERCENTAGE OF PALLIATIVE CARE PATIENTS NEEDING SPECIALIZED ASSESSMENT AND TREATMENT AND TO SERVE AS A FOCUS FOR EDUCATION AND RESEARCH. THIS DEVELOPMENT SHOULD OCCUR IN TWO STAGES, WITH UNITS BEING ESTABLISHED AT ST. JOSEPH'S HOSPITAL AND HENDERSON GENERAL HOSPITAL IN THE FIRST PHASE AND AT CHEDOKE-McMASTER HOSPITALS AND HAMILTON GENERAL IN THE SECOND PHASE. A COMPLETE EVALUATION OF THE EFFECTIVENESS OF THE FIRST PHASE UNITS SHOULD BE PERFORMED BEFORE THE DEVELOPMENT OF UNITS IN THE OTHER HOSPITALS.

Recommendation 6 (Priority #8):

THE TASK FORCE RECOMMENDS THAT THE BOARD OF DIRECTORS OF EACH HOSPITAL BE ASKED FOR A COMMITMENT TO PROVIDE ADMITTING POLICIES THAT FACILITATE THE ADMISSION OF PALLIATIVE CARE PATIENTS IN AN APPROPRIATELY EXPEDITIOUS MANNER.

Recommendation 7 (Priority #7):

THE TASK FORCE RECOMMENDS THAT PALLIATIVE CARE SERVICES IN THE REGION INCLUDE THE STRENGTHENING OF THE HOME CARE PALLIATIVE CARE PROGRAMME WITH A MORE EFFECTIVE LIAISON WITH HOSPITAL CONSULTATION TEAMS.

This would include financial coverage through the Provincial Home Care Programme for: patients on day passes from hospital, attendant/sitter and registered nurse 24-hour coverage when necessary, equipment such as



suction machines, air mattresses, Hoyer lifts regardless of the length of time on the programme and when necessary to provide palliative care in the home as well as involvement in the implementation of the Operational Plan of the Regional Programme (Appendix X).

#### 4. Services Needed

Palliative care services fall into the three traditional divisions of all health care services: (1) patient and family services, (2) education, and (3) research. Patient services fall into three main categories as well: (1) symptom control, (2) psychosocial and spiritual counselling, and (3) support services such as physiotherapy, nutrition and home support. Education includes education of the patient, family and the general public as well as all disciplines and levels of health professionals and volunteers. Research involves evaluation of present services and formalized research protocols around such issues as symptom control and cost-effectiveness of services.

In Hamilton-Wentworth, perceived needs and gaps have been identified in all three areas. Major issues include: (1) lack of financial support for patients at home, (2) a lack of a comprehensive bereavement follow-up programme, (3) the need for methods and tools to improve communication between all personnel providing palliative care services, (4) coordination of services offered to all palliative care patients in the region, (5) public and professional education around palliative care principles and practice, (6) the need for funding for palliative care staff in all institutions/agencies, and (7) the need for research.

Duplication of services has also occurred, mainly in the areas of patient assessment and bereavement follow-up.

As demonstrated in the inventory, each palliative care service in the region has developed separately. There has been no regional coordination to ensure that all the various component parts are in place to provide comprehensive palliative care services to all patients in the region requiring palliative care.



Hatch (11) indicates that, "Hospice programs can develop multi-institutional arrangements to ensure high-quality care and to plan for orderly distribution and location of programs." He also stresses the advantages of a regional network. These include: (1) back-up support for key personnel, (2) additional management sophistication, particularly in developing evaluation programmes, (3) sharing of educational resources, (4) improved planning capability which will increase availability and accessibility of a programme to all clients in need of its services, and above all, (5) improved care for terminally-ill patients and their families by collaborating in research and sharing resources, professional developments and skills.

The Hamilton-Wentworth District Health Council has as one of its ongoing priorities the rationalization of hospital-based clinical services into district programmes. The "Programmatic Approach" as it is called refers to the area-wide planning and organization of health care facilities and services into an effective, efficient and economical system to provide comprehensive programmes of health care, covering the entire spectrum of care and available to all on an area-wide basis (See Appendix XI).

This reorganization of health services from an institutional basis to a programmatic basis assures the best use of limited resources in providing comprehensive health care. The Honorable Larry Grossman, Past Minister of Health, recently noted that, "for examples of regionally integrated services, we might look at Hamilton. In that city, treatment resources have been concentrated in designated institutions as part of a regional plan, to ensure that centres of expertise develop in specific fields." (8).

So, based on the observations of key informants, the indicated need for a regional network and the policy of the Hamilton-Wentworth District Health Council toward rationalization, the Task Force makes the following recommendation:

Recommendation 8 (Priority #1):

THE TASK FORCE RECOMMENDS THE DEVELOPMENT OF A REGIONAL PALLIATIVE CARE PROGRAMME SIMILAR TO THE OTHER REGIONAL, INTERDISCIPLINARY PROGRAMMES IN HAMILTON-WENTWORTH TO ADDRESS ITSELF TO THE ISSUES OF PALLIATIVE CARE SERVICE, EDUCATION AND RESEARCH.

IN ADDITION, THE TASK FORCE RECOMMENDS THAT THE REGIONAL PALLIATIVE CARE PROGRAMME COLLABORATE WITH OTHER REGIONAL PROGRAMMES, EG., EMERGENCY SERVICES AND ONCOLOGY TO PROVIDE MORE COMPREHENSIVE SERVICES.

The suggested structure for the Regional Palliative Care Programme is shown in the Figure opposite (page 86).

Recommendation 9 (Priority #2):

THE TASK FORCE RECOMMENDS THAT A CHAIRPERSON BE DESIGNATED TO COORDINATE PALLIATIVE CARE SERVICES, EDUCATION AND RESEARCH. IN VIEW OF THE TIME COMMITMENT INVOLVED IN THE FORMATIVE YEARS OF THE PROGRAMME, THE TASK FORCE FURTHER RECOMMENDS THE FUNDING OF A HALF-TIME POSITION - A REGIONAL COORDINATOR - FOR A MINIMUM OF THREE YEARS.

Various sources could be approached for funding: (1) special Ministry of Health funding for pilot projects, (2) shared allocation of funds from the hospitals, (3) grants from hospital foundations, or, (4) the position could be included in the global budget of a unit.

These two recommendations are considered the first priority by the Task Force. A comprehensive operational plan for the programme is suggested in Appendix X.

REGIONAL PALLIATIVE CARE PROGRAMME  
ORGANIZATIONAL STRUCTURE

HAMILTON-WENTWORTH  
DISTRICT HEALTH COUNCIL

PALLIATIVE CARE PROGRAMME:

- Chairperson/Regional Coordinator
- Chairperson of standing committees
- Inpatient Facility representatives
- Community Health Care representatives
- Regional Oncology Programme Supportive Care Committee representative

PATIENT & FAMILY  
SERVICES COMMITTEE:

- inhospital
- home
- transportation
- communication
- coordination of services
- bereavement

EDUCATION COMMITTEE:

- 'rounds'
- medical - under & post graduate
- nursing - under & post graduate
- continuing
- other disciplines
- volunteers

RESEARCH COMMITTEE:

- define questions
- define studies & carry them out with help of involved institutions

5. Types of Personnel

Mount (22) suggests that a palliative care team should be able to respond to the patient's needs on an "as needed" basis and that special services, medical, allied health personnel, legal, financial and religious should be available on a consultant basis.

Key informants suggested increased, organized support for the consultation team through counselling, peer support meetings, and the holding of conferences at home or in the hospital which involve all of the groups involved in palliative care. They also implied the need to identify, in palliative care, a point of entry or method of extending services for various disciplines.

The Task Force feels that these supportive resources should be made available to the consultation teams referred to in recommendation #4, and so recommends the following:

Recommendation 10 (Priority #9):

THE TASK FORCE RECOMMENDS THE DEVELOPMENT OF A SUPPORT/RESOURCE GROUP BY THE PALLIATIVE CARE CONSULTATION TEAMS DESCRIBED IN RECOMMENDATION 4. THIS GROUP SHOULD CONSIST OF OTHER HEALTH CARE DISCIPLINES - PHARMACY, PHYSIOTHERAPY, NUTRITION AND OTHERS WITH AN INTEREST AND EXPERTISE IN PALLIATIVE CARE TO PROVIDE SERVICES AS NEEDED.

6. Eligibility Criteria

Eligibility criteria for palliative care relate to a number of issues. Included are type of disease, stage of disease, symptomatology exhibited, area of residence and acceptance of the concept of care offered. In addition, criteria for admission must be based on the accepted definition and standards for each programme as well as on its philosophy of palliative care and its existing resources. Eligibility criteria in the existing programmes in Hamilton-Wentworth are quite consistent and readily adaptable to a regional definition and standards of palliative care as demonstrated in the tables in the inventory.

Recommendation 11 (Priority #5):

THE TASK FORCE RECOMMENDS THAT THE REGIONAL PALLIATIVE CARE PROGRAMME, THROUGH DISCUSSIONS WITH SERVICE PROVIDERS, ESTABLISH ELIGIBILITY CRITERIA FOR PALLIATIVE CARE PROGRAMMES THROUGHOUT THE REGION. THESE CRITERIA SHOULD REFLECT THE ACCEPTED DEFINITION AND STANDARDS OF THE REGIONAL PROGRAMME BUT ALLOW FOR SOME DIVERSITY TO REFLECT SPECIAL INTERESTS AS WELL AS EXISTING RESOURCES.

7. Economic Issues

Economic concerns in the area of palliative care are described in the Financial section of Table 9. In addition, the Task Force recognizes that many of the elements noted under Services Needed and Education in Table 9 as well as some of those under Coordination would require funding to implement. Unfortunately, there is a dearth of information in the literature that would tell us which are the most effective measures to implement. Patricia Parks (23) makes several points relating to economic issues. These include: (1) that dying patients are among the sickest and most costly patient in today's health care system, (2) that in an era of economic restraint and limited resources, all health care services are being carefully assessed in terms of efficacy and cost-effectiveness, (3) that because a health care concept is inherently good it cannot automatically be integrated into the existing system, and finally, (4) that the burden of proof of the value of palliative care in the health care system rests with its proponents. She also states, "It is time to study hospice care through controlled, scientific means to prove that hospice care is an effectual, replicable and cost-effective form of care for dying patients and their families."



Robert Buckingham and Susan Foley (4) support this view saying, "The lack of substantiating evidence in support of presently operative theories, the obvious need for better care and the pending support of many service facilities all call for documentation to replace the overabundance of conjecture and opinion in the field of death and dying with a solid foundation on which to base action programmes." He adds, "In order to justify continuation as well as the proposed extension of the hospice concept, proof of programme legitimacy and effectiveness is required."

In Hamilton-Wentworth, as in most areas involved in palliative care services at present, very little statistical information has been collected. It is even difficult to determine for most services the per diem cost per patient to the institution or agency, let alone to consider the cost-effectiveness of the dollar spent. Consequently, the Task Force makes the following recommendation in order to assist the suggested palliative care programme in dealing with the concerns raised around this issue:

Recommendation 12 (Priority #14):

THE TASK FORCE RECOMMENDS THE INITIATION OF A COMPREHENSIVE COST-EFFECTIVENESS STUDY OF PALLIATIVE CARE SERVICES IN THE REGION. IT FURTHER RECOMMENDS THAT THE STUDY BE DONE UNDER THE AUSPICES OF THE REGIONAL PALLIATIVE CARE PROGRAMME WITH THE ASSISTANCE OF THE DEPARTMENT OF CLINICAL EPIDEMIOLOGY AND BIOSTATISTICS AT McMASTER UNIVERSITY.

Since both hospital consultation and Home Care programmes are already in existence in Hamilton-Wentworth, a study of this nature is feasible in this region.



## 8. Education

Education in palliative care is one of the most frequently perceived needs identified in the responses from key informants in the survey. Two target groups for education were identified: (1) the general public, including patients and families, and (2) all health professionals, including those working in hospitals, community agencies, nursing homes, etc., and including palliative care volunteers. Public Education concerning issues around grief, death, the philosophy of palliative care, and the resources available for patients and their families should be the responsibility of all health professionals involved in palliative care. The onus for educating other health professionals concerning these issues also lies with this group. In addition, undergraduate, postgraduate and continuing education programmes for health professionals need to address issues which further the understanding of palliative care concepts and develop sound palliative care methodology.

A variety of methods can be used to disseminate palliative care education - lectures, workshops, service rounds, and student placements.

Coordination between all palliative care services is essential to provide palliative care education in the most effective and efficient manner, to reach the highest number of people, to avoid duplication and to prevent untoward strain on the providers.

The need for palliative care education has been well documented in the literature and is included in the standards set down by the International Work Group on Death, Dying and Bereavement (22).

Recommendation 13 (Priority #10):

THE TASK FORCE RECOMMENDS THAT PALLIATIVE CARE EDUCATION BE COORDINATED BY THE REGIONAL PALLIATIVE CARE PROGRAMME TO INCLUDE UNDERGRADUATE, POSTGRADUATE AND CONTINUING EDUCATION FOR HEALTH PROFESSIONALS AND CLERGY IN ALL SETTINGS, AS WELL AS EDUCATION FOR VOLUNTEERS AND THE PUBLIC.

9. Research and Evaluation

Two areas for consideration concerning research in palliative care were identified in the inventory of services. The first is the evaluation of present services. Most programmes offering palliative care services in the Hamilton-Wentworth region are in the very preliminary stages of data collection if they are involved in it at all. The methods and tools available are unique to each service, making comparison of services difficult. There is a need for the development of standardized tools which will translate goals into measurable outcomes which can be used to assess both institutional and community-based programmes. These will provide a basis for evaluation which can identify the strengths and weaknesses of existing services and allow programme planners to plan more effectively.

The development of standardized evaluation tools for the region will, in addition to providing more comparable data, conserve time and money for the individual programmes involved.

In addition to recommending a cost-effectiveness study (Recommendation 12), the Task Force also recommends the following:

Recommendation 14 (Priority #13):

THE TASK FORCE RECOMMENDS THE DEVELOPMENT OF A STANDARDIZED DATA COLLECTION SYSTEM TO FACILITATE THE AUDIT OF EXISTING PALLIATIVE CARE SERVICES, WHETHER INSTITUTIONAL OR COMMUNITY-BASED.

\* \* \* \* \*

In summary, this chapter sets out the recommendations of the Palliative Care Task Force of the Hamilton-Wentworth District Health Council. It also attempts to demonstrate the rationale behind the recommendations and the conclusions formulated on the basis of the literature review and the survey of existing services and perceived needs and gaps in palliative care services in the region.

Central to the recommendations is the establishment of a Regional Palliative Care Programme whose structure, reporting mechanism and functioning would be similar to other regional programmes reporting to the District Health Council.

As viewed by the Task Force, the Regional Programme will be the logical body to oversee the implementation of the remainder of the recommendations, thus providing direction and coordination, with a direct communication link to the Health Council.

At the same time, the Home Care Programme should be strengthened and the expansion/development of teams and units in each institution, as recommended, should be initiated. The development of a comprehensive bereavement follow-up programme should be undertaken by an ad hoc subcommittee of the Patient and Family Services Committee of the Regional Programme. In keeping with the concept that bereavement is a normal, self-limiting process that rarely needs professional intervention, the Task Force suggests

that the chairperson of this committee should be from outside the medical realm. The committee should have appropriate membership from concerned groups in the community. These should provide a system of palliative care services that will allow the patient to remain in his home as long as possible while providing the availability of hospital care when necessary and appropriate support services for the family.

The recommendations are listed, in order of priority, in the Executive Summary (page vii).

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# Hamilton-Wentworth District Health Council

## Appendix I

### PALLIATIVE CARE QUESTIONNAIRE

#### *I Demographic Data:*

#### *II Description of the Programme:*

1. Give your organization's definition of palliative care.
2. List the objectives of your programme.
3. Identify any administrative/advisory group including membership, time commitment, issues identified and resolved.
4. Describe the type of services that your organization provides including type of personnel involved, and the time each individual commits to palliative care per day.
5. Identify all sources of funding for palliative care services within your organization.
6. Indicate the duration of funding.
7. Indicate the cost to the client for the services provided.
8. Indicate the per diem cost per patient to the organization for services rendered.
9. Indicate the number of direct patient care hours per patient per day utilizing a range of time.
10. (a) Identify what access to staff support, either formal or informal, is available for individuals involved in palliative care.  
(b) How frequently is it utilized?
11. (a) Describe any plans for expansion or reduction of services.  
(b) Have these plans been tabled for funding?
12. Describe the educational activities in the palliative care area within your organization in the year January 1982 to December 1982 including, (a) the number,  
(b) types, and  
(c) composition of audience for presentations, seminars, etc.  
(d) Also indicate the number and types of students associated with palliative care in the same time span as well as the length of time on the service.



-2-

13. Describe any involvement in formalized research in palliative care within your organization.
14. Describe methods of evaluating present palliative care services in your organization.
15.
  - (a) Describe the method of access to hospital beds for palliative care outpatients.
  - (b) Is there any priority status given to palliative care admissions?
  - (c) Is there access to the appropriate unit for the patient?

### III Eligibility: Inclusion and Exclusion Criteria

1. What types of diagnoses do you accept for care?
2.
  - (a) What prognosis do patients you accept for care have?
  - (b) Is there a defined time factor?
3. What age groups do you accept for care?
4. Is the service offered to both males and females?
5.
  - (a) From whom do you accept referrals to the service?
  - (b) Does the attending physicians have to be notified of the referral on all patients?
6.
  - (a) How often do language and/or cultural barriers become a problem in eligibility for care?
  - (b) Describe the problem.
  - (c) How is it handled?
7. Define the geographic area served by your organization's palliative care services.
8. Is there any difficulty in moving the patient on the cure $\rightleftharpoons$ care continuum as needs indicate? Describe any difficulties.

### IV Utilization:

1. Identify, if possible, the average number of patients you are able to see per week?
2. Describe the coverage for services your organization provides (hours of operation) for palliative care.
3. Do you have a waiting list for palliative care services? Identify, if possible, the number of referrals that cannot be handled.



-3-

4. Please list an approximate range of time from referral to action for the following services:

- (a) Consultation:
- (b) Involvement in direct care:
- (c) Counselling:

Describe your admission to service statistics under:

5. Geographical area (a) Hamilton-Wentworth (i) urban  
(ii) rural

(b) outside Hamilton-Wentworth (i) urban  
(ii) rural

6. Age -  
(a) < 35  
(b) 36 - 55  
(c) > 55

7. Sex - M  
F

8. What is your average length of stay on service or duration of your follow-up?

9. From whom do you get referrals in palliative care patients?

10. To whom do you refer palliative care patients?

11. Could you provide discharge statistics under -  
(a) Discharge from service?  
(b) Deaths?

PALLIATIVE CARE DATA COLLECTION TOOL

## I. DEMOGRAPHIC DATA:-

Programme \_\_\_\_\_

Year established \_\_\_\_\_

Agency \_\_\_\_\_

Phone \_\_\_\_\_

Head of Programme \_\_\_\_\_

Respondent's name \_\_\_\_\_

Position \_\_\_\_\_

Length of involvement with  
palliative care \_\_\_\_\_

## II. Description of Programme:-

Definition of "P.C." (starting point  
services needed, end point).

Objectives of programme:-

TYPE OF SERVICE	CONSULTING TEAM	UNIT	HOME VISITING	COUNSELLING SERVICES	OP/DAY CARE	BEREAVEMENT FOLLOW-UP	OTHER
M E P M N B PL E SW R PT/OT S D H C I V P O							
FUNDING SOURCE							
DURATION OF FUNDING							
COST TO CLIENT							
PER DIEM COST PER PT TO AGENCY							
# CARE HOURS							
STAFF SUPPORT							
EXPANSION REDUCTION							
EDUCATIONAL FUNCTION							
RESEARCH							
LINKAGE & LIAISON ACCESS TO HOSP.BED							

# III ELIGIBILITY: INCLUSION AND EXCLUSION CRITERIA

TYPE OF SERVICE	CONSULTING TEAM	UNIT	HOME VISITING	COUNSELLING SERVICES	OP/DAY CARE	BEREAVEMENT FOLLOW-UP	OTHER
DIAGN.							
PROGNOSIS							
AGE							
SEX							
REFERRAL SERVICE							
LANG. & CULTURAL BARRIERS							
GEOG. AREA SERVED							
ACCESS TO MOVE CURE-CARE							
COMMENTS:-							

TYPE OF SERVICE	CONSULTING TEAM	UNIT	HOME VISITING	COUNSELLING SERVICES	OP/DAY CARE	BEREAVEMENT FOLLOW-UP	OTHER
PROGRAMME CAPACITY							
HOURS OF OPER COVERAGE							
WAITING LIST SIZE							
TIME LAPSE TO SEE RERERRALS							
ADMISSIONS 80-81							
GEOG. AREA							
ADMISSIONS AGE							
ADMISSIONS SEX							
AVERAGE LENGTH OF STAY OR DURATION OF FOLLOW-UP							
REFERRALS TO SERVICE							
REFERRALS FROM SERVICE							
DISCH/DEATH							

COMMENTS:--

V PERCEPTIONS:-

1. Could you tell me what, if any, unmet needs or gaps in services you perceive in the area of P.C. in the region.  
(target group)
2. Have you identified any duplication of services in P.C in the Region?
3. How do you feel P.C. services in the Region could be better co-ordinated?
4. Are the clients referred to you appropriate for the services you offer?



# Hamilton-Wentworth District Health Council

## Appendix III

### FAMILY PHYSICIAN SURVEY

*The Palliative Care Task Force is interested in any unmet needs or gaps that you perceive in the area of palliative care in Hamilton-Wentworth. Please list your comments and concerns under the following categories, which were identified in a preliminary survey of palliative care services.*

- 1. Financial support (for services, programmes, specific target groups, etc.):*
- 2. Communication between individuals and agencies involved in patient care:*
- 3. Coordination of services to provide continuous, high quality patient care:*
- 4. Education (public and professional):*
- 5. Services (expansion or reduction of present services; additional services required):*
- 6. Other needs/gaps:*

*Please indicate whether you are in group or solo practice \_\_\_\_\_*

*\*Please detach and return in the enclosed stamped envelope by March 23, 1983.*

*Thank you for your assistance.*

*/ch*

PALLIATIVE CARE ADMINISTRATIVE/ADVISORY STRUCTURE

ST. JOSEPH'S HOSPITAL, HAMILTON

CONCEPTUAL MODEL - ORGANIZATIONAL CHART

The Palliative Care Consultation Program is Hospital-Wide. It relates through the Chief of the Department of Medicine to the Medical Advisory Committee.

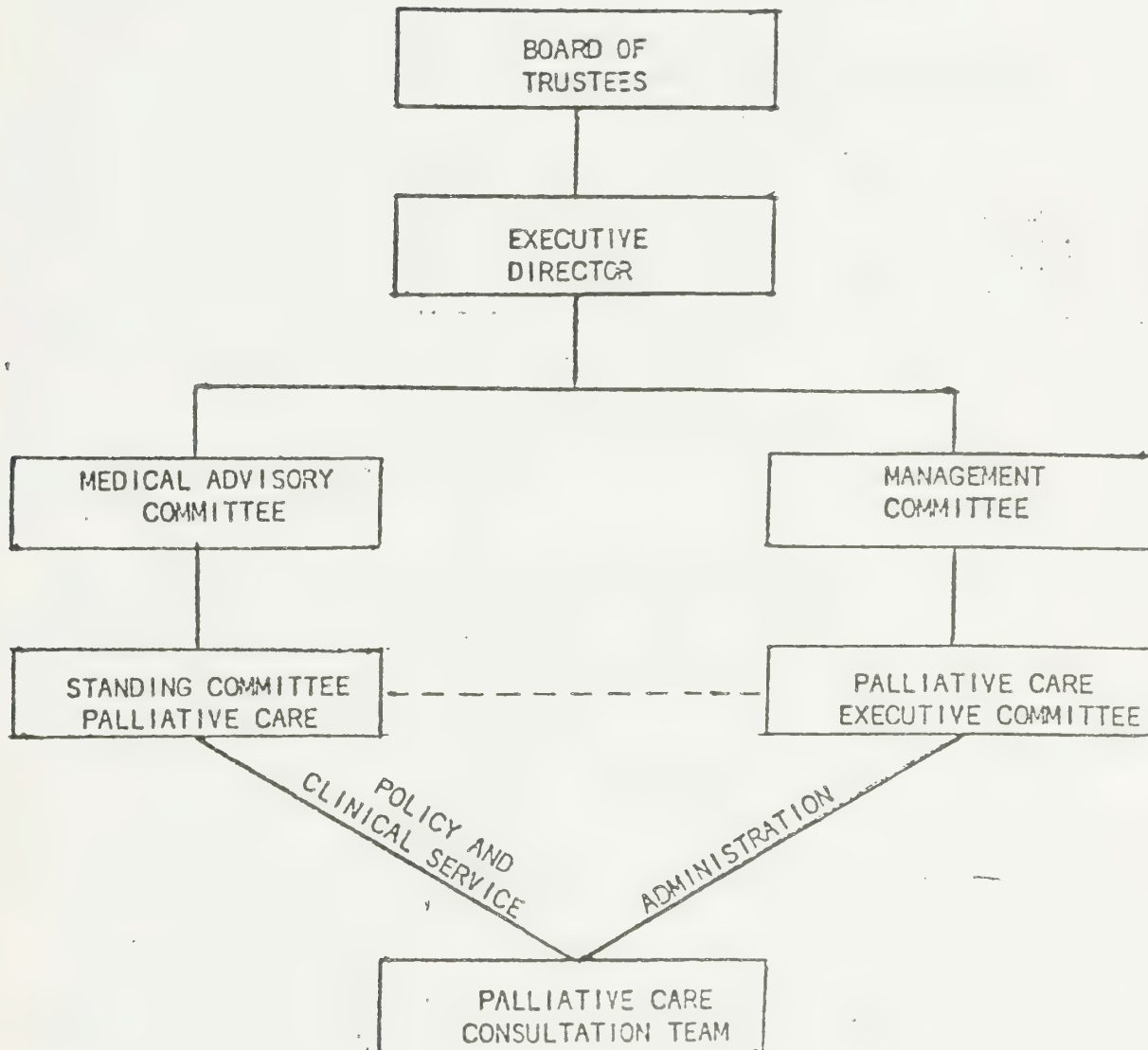
Its policy/consultation functions are monitored by the Palliative Care Committee, who are responsible for the Program. This committee is a standing committee of the Medical Advisory Committee.

Administratively, the Program is monitored by the Palliative Care Executive Committee. Its Chairperson, the Director of Nursing, as a member of the Hospital Executive, reports its activities directly to the Management Committee. In turn, the Executive Director relates matters regarding Palliative Care from this Committee to the Board of Trustees.

The following chart illustrates the position, relationships and lines of accountability of the service within the broader hospital organizational structure.

# PALLIATIVE CARE CONSULTATION TEAM

## ORGANIZATIONAL CHART



- NURSING CO-ORDINATOR - DEPARTMENT OF NURSING
- CLINICAL DIRECTOR/CONSULTING PHYSICIAN - MEDICAL ADVISORY COMMITTEE
- SOCIAL WORKER - DEPARTMENT OF SOCIAL WORK
- PASTORAL CARE LIAISON - DEPARTMENT OF PASTORAL CARE
- VOLUNTEERS - VOLUNTEER DEPARTMENT

St. Joseph's Hospital  
Hamilton Ontario  
Palliative Care Consultation Team

ADMINISTRATION/ADVISORY GROUPS

1. BOARD OF TRUSTEES - In April 1980 recommended the establishment of a palliative care service with funding for a nurse, a social worker and a part-time physician for the budget year 1980-81.
2. MEDICAL ADVISORY COMMITTEE - recommended on March 4th, 1980 the establishment of a palliative care service for the hospital.
  - i) Nursing Co-ordinator:  
Responsible for overall program and service development, as well as care planning and case management.
  - ii) Consultant Physician:
    - Provision of patient service individually or in conjunction with attending/family physician and/or consultants.
    - Facilitation of planning and management of regime for pain and symptom control.
  - iii) Social Worker:
    - Responsible for psychosocial support for patient, family and staff.
    - Training and supervision of volunteers

A combined role for all Team members is facilitation of communication between physicians, nursing and other hospital staff, patient, family and other support persons. Education is also provided by all Team members to Health Professionals and other interested professionals and lay persons.

3. PALLIATIVE CARE ADMINISTRATIVE GROUP

TERMS OF REFERENCE:

1. The purpose of this committee is to undertake administrative functions for the group, such as budget review and co-ordinating activities with hospital departments.
2. To be a resource for the team.
3. To refer appropriate clinical matters to the Palliative Care Committee.
4. To provide liaison with Management Committee.

MEMBERSHIP: - Director of Nursing  
Director of Social Work  
Pastoral Care Co-ordinator  
Medical Director, Palliative Care Team  
Nursing Co-ordinator, Palliative Care Team  
Social Worker, Palliative Care Team  
Chairman of Palliative Care Committee

4. PALLIATIVE CARE COMMITTEE

TERMS OF REFERENCE:

1. The purpose of this committee is to monitor and recommend policy for Palliative Care Service throughout the hospital.
  2. To receive and act upon recommendations of the Palliative Care Administrative Group.
  3. Minutes of all meetings are maintained and forwarded to the Medical Advisory Committee.
- Frequency of meetings: - The committee meets every other month, subject to confirmation by the chairman.

MEMBERSHIP: - Medical Director of the Palliative Care Team  
- Representation from Medical Staff to include:  
a) Department of Surgery, b) Department of Family Medicine  
c) Department of Anesthesiology (d) Department of Internal Medicine  
- Representation from the following departments:  
a) Nursing b) Physiotherapy - Dietary Department  
c) Social Work d) Pastoral Care  
e) Pharmacy f) Home Care Program  
g) Public Health h) Director of Volunteers  
- Members of Palliative Care Consultation Team:  
Nursing Co-ordinator  
Social Worker

Palliative Care Consultation Team  
January, 1983

EDUCATIONAL INVOLVEMENT - PALLIATIVE CARE

Henderson General Hospital

July 1, 1982 - December 1, 1982

LISTED CHRONOLOGICALLY

- \* 1. July - September 1982 - Pain Seminar Series - Henderson General Hospital  
1 hour per week x 8 weeks  
Audience - nurses, physicians and housestaff
2. July 21, 1982 - Hamilton General Hospital, C.T.U. Ward 35 Housestaff  
Palliative Care
3. July 28 & August 18, 1982 - Seminar - Family Practice - Hamilton General Hospital  
Control of Cancer Pain - 1 hours
4. August 4, 1982 - Seminar - Pharmacist Group and Trainees  
Pain Control - 2 hours
5. August 11, 1982 - Ward 395 (Oncology) - Introductory Seminar for O.T.  
Physio, Home Care - Palliative Care
6. August 17 & August 24, 1982 - Seminars - 1 hour each  
Housestaff - C.T.U. - Henderson General Hospital  
1) Palliative Care  
2) Pain Control
7. September 2, 1982 - Family Medicine - Henderson General Hospital  
2 hours - Palliative Care
8. September 8, 1982 - Regional Gynecology Oncology Rounds - Henderson  
General Hospital - Pain Control
9. September 16, 1982 - Ward 395 - Nursing Group -  
Palliative Issues
10. September 22, 1982 - Phase IV Family Medicine - Seminar - 1 hour  
Palliative Care
11. September 29, 1982 - Community Nursing Registry Nurses - 2 hour Seminar  
Palliative Care
12. October 14, 1982 - Regional Oncology Program - Research Rounds - 1 hour  
Issues in Pain Control



-2-

13. October 25, 1982 - Cancer Clinic - Regional Oncology Programme -  
Psychosocial Rounds - 1 hour  
Palliative Care
  - \* 14. October 18 -  
November 22, 1982 - Academic Studies, MUMC, 2½ hours per week  
- nurses, physicians, other  
Palliative Care
  15. November 4, 1982 - Regional Oncology Rounds - 1 hour  
- oncology, housestaff, nurses  
- Pain Control
  16. November 5, 1982 - Halton County Public Health  
- nurses - half day seminar  
- Palliative Care
  17. November 9, 1982 - Hamilton Association of Christian Churches  
- 1 hour  
- Palliative Care
  18. November 12, 1982 - Nursing Rounds, Henderson General Hospital  
- 3 hours (2 sessions), general staff nurses  
- Palliative Care
  19. November 18, 1982 - St. Elizabeth Nurses  
- 1½ hours  
- Palliative Care
  20. November 24, 1982 - Hamilton General Hospital - Administrative Nursing Group  
- 45 minutes  
- Palliative Care
  21. November 24, 1982 - C.M.E. Day in Medicine  
- 45 minutes  
- Pain Control in the Terminally Ill
  22. December 1, 1982 - Resource Session, Phase IV  
- 1 hour  
- Palliative Care
- In addition:
1. Resident 3 affiliated with the team 0.5 time for 8 weeks January & February, 1983.
  2. A pain management booklet has been prepared for use in hospital and on wards.
  3. An educational brochure is being assembled to mail to in-town and out-of-town family physicians and consultants with whom we are involved.

EDUCATIONAL INVOLVEMENT - PALLIATIVE CAREST. JOSEPH'S HOSPITAL

<u>EDUCATIONAL FUNCTION</u>	<u>AUDIENCE</u>	<u>PRESENTERS</u>	<u>FREQUENCY</u>	<u>SESSION LENGTH</u>
1. Nursing Staff, Physio, O.T., Dietary, Pharmacy Social Work, Pastoral Care		Nursing and social work team members	Average once a month	.5 to 2.0 hours
2. Staff Physicians Rounds - Family Medicine - Surgery Individual Physician Groups		Consultant Physician	Average once in 3 months	1.0 hours
3. Medical Students House Staff		Team	every 3 months	1.0 hours
4. Volunteers		Nursing and social worker team members	(1) once every month update (2) once a week for six weeks yearly - Education for new volunteers	2.0 hours 2.0 hours
5. Outside Groups (1 - 2 x each) Community Nursing Groups Service Clubs, Paramedics, Church Groups, C.A.S. Memorial and Funeral Groups, Radio - T.V. - Press		Team or individual members of team	Average once a month	1 - 2 hours

TOTAL 1982 EDUCATIONAL REFERRALS --- 77

The team has been involved as a resource for community palliative care at the request of family physicians and/or private nursing agencies. This can be solely as resource or can be as resource plus direct involvement for pain and symptom management and psychosocial support for patient and family.

In addition, an M.H.Sc. student was affiliated with the team for clinical experience from September - December 1982.

# Hamilton-Wentworth District Health Council

Manastorium Road  
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February 2, 1983

MEMO TO: Dr. D.J.J. Kraftcheck, Chairman  
Palliative Care Task Force

FROM: Mrs. Carol Hayter, Chairman  
Health Professions Coordination Group 'A'

RE: Input to the Task Force from Health Professionals in the  
District

---

At our most recent meeting, the Health Professions Coordination Group 'A', comprised of representatives of the various health professional associations in the district, discussed the area of palliative care. Members had previously approached their respective associations and came to the meeting with input on professional experience of problems with existing service provision, unmet needs, gaps, duplications and possible solutions.

Through a group consensus process, four main issues were raised with contributing issues identified. These are listed here as possible input to the deliberations of your Task Force:

1. Education:

- of patients and families around
  - a) nutritional issues
  - b) pain management
- of professionals around:
  - a) nutritional issues
  - b) pain management
  - c) utilization of physiotherapists, occupational therapists, pharmacists and chiropractors as consultants for patient care in institutions and community
  - d) needs of patient dying at home - family support
    - M.D. available to pronounce death
    - provision of beds in late terminal stages
  - e) need for identification of one case manager for each patient and family
  - f) the role of the Cancer Clinic in the community and the services it provides
  - g) need for controlling the number of persons involved in patient-family care and avoiding duplication of services
  - h) need for bereavement follow-up.

Cont'd...

# Hamilton-Wentworth District Health Council

## 2. Communication:

- identification of appropriate times to make referrals to various health team members (occupational therapist, physiotherapist, pharmacist, nutritionist) and methods of doing so, in institutions and community
- travelling record for patients
- formalized committee for provision of information and coordination of available services

## 3. Standards:

- to be utilized by all professionals involved in palliative care in institutions and community around such issues as:
  - a) education
  - b) pain management
  - c) nutrition
  - d) home deaths
  - e) bereavement follow-up
  - f) volunteer education and services

## 4. Coordination:

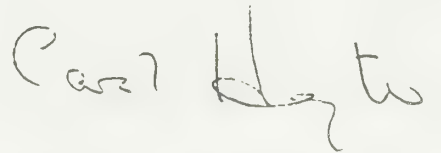
- consideration of membership in palliative care team (including occupational therapist, physiotherapist, pharmacist, nutritionist)
- appropriate referrals to various health team members at optimum time for services
- utilization of chiropractors in palliative care in institutions/ community
- continuous development of palliative care programmes with the possibility of the development of a palliative care unit in the community
- identification of one case manager for each patient and family
- identification in palliative care of a point of entry or method of extending services for various disciplines (occupational therapists, physiotherapists, pharmacists, nutritionists, chiropractors)
- formalized committee for the provision of information and coordination of available services

Cont'd....

4. Coordination (cont'd):

- coordination of care for patients dying at home:
  - a) availability of M.D. to pronounce death
  - b) family support
  - c) provision of beds for late terminal cases
- funding for particular equipment, services, personnel needed  
e.g. dressings and equipment for private duty patients;  
bereavement follow-up
- coordination of volunteer education and services throughout  
community
- method of controlling the number of persons involved in  
patient-family care and avoiding duplication of services

I trust that this input will be helpful in your examination of palliative care. Should your Task Force require any further input on specific issues from the Health Professions Coordination Group, do not hesitate to contact me.



Carol Hayter, Chairman  
Health Professions Coordination Group 'A'

CH/jm



INTERNATIONAL STANDARDS OF CARE FOR THE TERMINALLY ILL

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## International group issues proposal for standards for care of terminally ill

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BALFOUR M. MOUNT, FRCS[C]

The International Work Group on Death, Dying and Bereavement first met in November 1974. At that meeting a small group, the standards committee, was formed to delineate the standards of care essential for dying patients, the role of their families and the support system for the care givers. At subsequent meetings of the work group, held every 18 months, the standards committee has continued this work, and its members have continued to meet in small groups whenever there was an opportunity.

No one at that first conference realized how rapidly the hospice movement would evolve; how widespread it would become or how urgently these standards would be needed.

At its most recent conference in January 1978, the committee decided that the following document should be published in its present form, stating the assumptions and principles underlying the standards, so that others could use them now, when they are so needed.

Underlying the document was the idea that while institutions need guidelines to develop standards, each setting must develop its own standards based on certain key assumptions and principles. This position was first proposed in an editorial in *Omega* (7: 191, 1976).

There was general agreement among the members that further editing must be done, and that regularly planned times to review and revise must be scheduled.

This document has been accepted for publication by the *American Journal of Nursing*; publication in the *Journal of the American Medical Association*, the *Lancet* and other journals is being negotiated.

It is hoped that before the document's next review at the June meetings of the International Work Group on Death, Dying and Bereavement, to be held in Mont Ste-Marie, Quebec, readers will correspond with the committee chairman or any of its members to comment on the strengths and weaknesses in the document and to propose changes.

The members of the committee are care givers from many disciplines — divinity, medicine, nursing and social work — and social scientists in anthropology, psychology and sociology.

Correspondence about this document should be addressed to Florence S. Wald, 101 Alps Rd., Branford, Connecticut 06405. Florence Wald is chairman of the standards committee and associate clinical professor, Yale University school of nursing.



## Patient-oriented

There are patients for whom aggressive curative treatment becomes increasingly inappropriate

The symptoms of terminal disease can be controlled

Patients' needs may change over time

Care is most effective when the patient's lifestyle is maintained and life philosophy respected

Patients are often treated as if incapable of understanding or of making decisions

Dying patients often suffer through helplessness, weakness, isolation and loneliness

The varied problems and anxieties associated with terminal illness can occur at any time of day or night

These patients need highly competent professionals, skilled in terminal care

The patient should be kept as symptom free as possible. Pain in all its aspects should be controlled. The patient must remain alert and comfortable

Staff must recognize that other services may have to be involved and that continuity of care should be provided

The terminally ill patient's own framework of values, preferences, and life outlook must be taken into account in planning and conducting treatment

Patients' wishes for information about their condition should be respected. They should be allowed full participation in their care, a continuing sense of self-determination and self-control

The patient should have a sense of security and protection. Involvement of family and friends should be encouraged.

Twenty-four hour care must be available seven days a week for the patient/family where and when it is needed

## Family-oriented

Care is usually directed towards the patient. In terminal illness the family must be the unit of care

The course of the terminal illness involves a series of clinical and personal decisions

Many people do not know what the dying process involves

The patient and family need the opportunity for privacy and being together

Complexity of treatment and time-consuming procedures can cause disruption for the patient, family or both

Patients and families facing death frequently experience a search for the meaning of their lives, making the provision of spiritual support essential

Survivors are at risk emotionally and physically during bereavement

Help should be available to all those involved whether patient, relation or friend to sustain communication and involvement

Interchange between patient, family and clinical team is essential to enable an informed decision to be made

The family should be given time and opportunity to discuss all aspects of dying, death and related emotional needs with the staff

The patient and family should have time alone and privacy both while the patient is living and after death occurs. A special space may need to be provided

Procedures must be so arranged as not to interfere with adequate time for patient, family and friends to be together

The religious, philosophic and emotional components of care are as essential as the medical, nursing and social components and must be available as part of the team approach

The provision of appropriate care to survivors is the responsibility of the team that gave care and support to the deceased

## Staff-oriented

The growing body of knowledge in symptom control, patient- and family-centred care and other aspects of the care of the terminally ill is now readily available

Good terminal care presupposes emotional investment on the part of the staff

Emotional commitment to good terminal care will often produce emotional exhaustion

Institutions and organizations providing terminal care must orient and educate new staff and keep all staff informed about developments as they occur

Staff needs time and encouragement to develop and maintain relationships with patients and relatives

Effective staff support systems must be readily available

## General

The care of the dying is a process involving needs of the patient, family and care givers

The problems of the patient-family facing terminal illness include a wide variety of issues: psychological, legal, social, spiritual, economic and interpersonal

Dying tends to produce a feeling of isolation

It has been the tradition to train care givers not to become emotionally involved, but in terminal illness the patient and family need to experience the personal concern of those taking care of them.

Health care services customarily lack coordination

A supportive physical environment contributes to the sense of well being of patients, of family and of care givers

The interaction of these three groups of individuals must constantly be assessed with the aim being the best possible care of the patient. This cannot be accomplished, however, if the needs of family, care giver or both are negated

Care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions and with commonness of purpose

All that counteracts unwanted isolation should be encouraged; social events and shared work, inclusive of all involved, should be arranged so that meaningful relations can be sustained and developed

Profound involvement without loss of objectivity should be allowed and fostered, realizing this may present certain risks to the care giver

The organizational structure must provide links with existing health care professionals in the community

The environment should provide adequate space, furnishings that put people at ease, the reassuring presence of personal belongings and symbols of life cycles

EXHIBIT A

**TABLE VIII**  
**New Cancer Cases Registered by Treatment Centre, 1971-1980<sup>1,2</sup>**

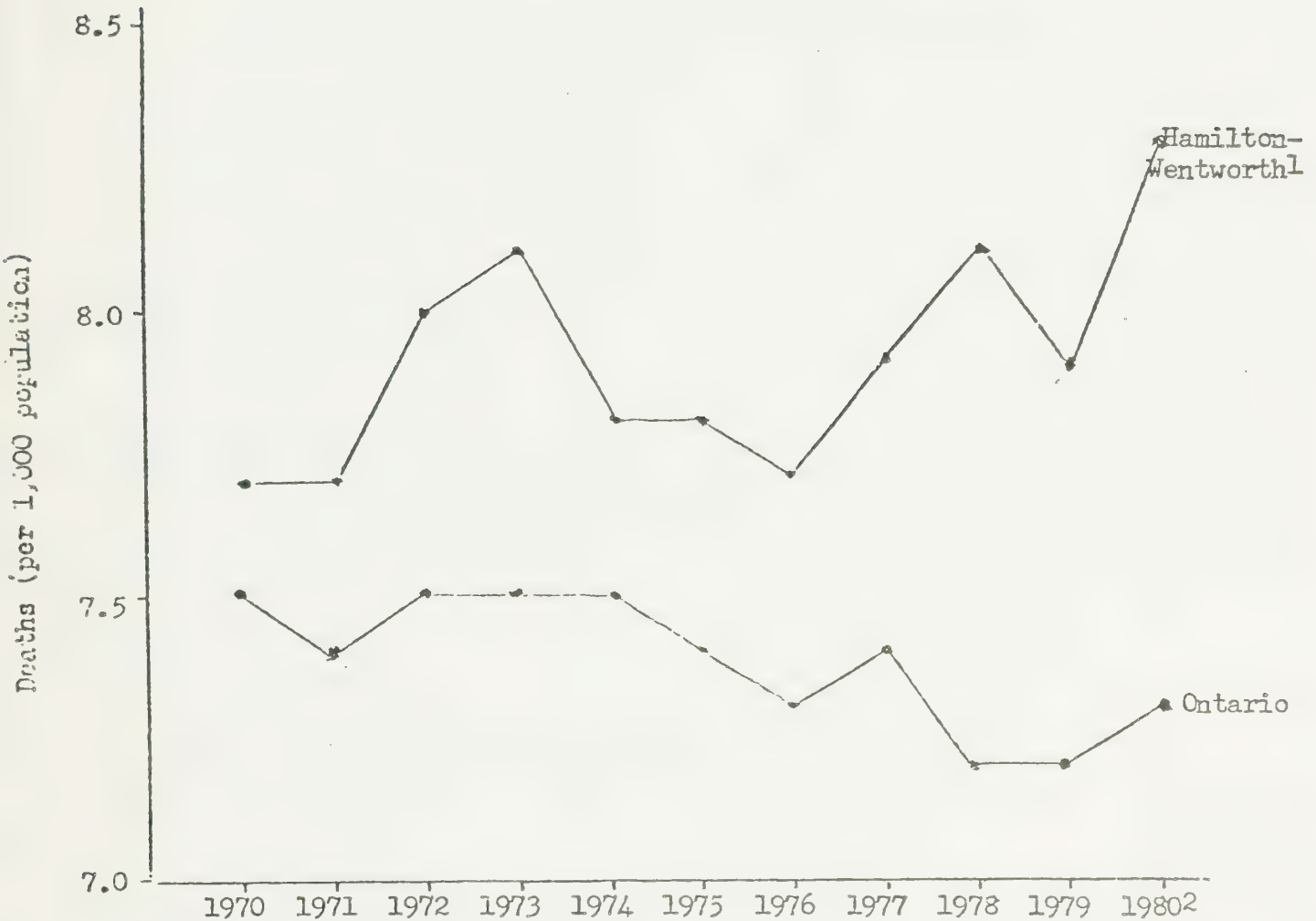
CENTRE	YEAR OF REGISTRATION									
	1971	1972	1973	1974	1975	1976	1977	1978	1979	1980
Hamilton	1,487	1,613	1,890	1,890	2,091	2,254	2,353	2,493	2,594	2,507
Kingston	676	921	932	887	921	816	988	1,040	999	984
London	2,012	1,988	2,111	2,254	2,359	2,460	2,344	2,488	2,537	2,583
Ottawa	1,187	1,363	1,423	1,502	1,525	1,631	1,759	1,902	1,997	2,078
Thunder Bay	211	236	300	313	313	399	365	412	369	401
Toronto:										
Princess Margaret Hospital	4,663	5,057	5,083	5,569	6,027	6,158	6,462	6,960	6,911	7,057
Bayview	—	—	—	—	—	—	—	—	—	441
Windsor	810	760	770	857	889	880	843	854	898	813
<b>TOTAL</b>	<b>11,046</b>	<b>11,938</b>	<b>12,509</b>	<b>13,272</b>	<b>14,125</b>	<b>14,698</b>	<b>15,114</b>	<b>16,149</b>	<b>16,305</b>	<b>16,864</b>

<sup>1</sup>Excludes carcinoma of cervix in situ.

<sup>2</sup>Any case registered at more than one treatment centre in a given year is allocated to the centre where it was first registered.

EXHIBIT B

DEATH RATES FOR HAMILTON-WENTWORTH AND ONTARIO  
(1970-1980)



<sup>1</sup>Rates for Hamilton-Wentworth have been calculated using actual assessed population figures obtained from the Planning Department of Hamilton-Wentworth and not the Registrar General's population estimates.

<sup>2</sup>Preliminary data for Hamilton-Wentworth.

Source: Province of Ontario, Vital Statistics, Registrar General, 1970-1980.

EXHIBIT C

NUMBER OF DEATHS IN ONTARIO WITH DIAGNOSIS OF NEOPLASM  
BY TOTAL AND MAJOR AGE GROUPS:1980-1981

	Total Deaths	Deaths due to Neoplasm
Provincial	40,268	11,183
Age Groups:		
0-14	440	75
15-44	1,713	630
45-64	8,531	3,787
65+	27,681	6,665

Exhibit C demonstrates that approximately 11,000 deaths in Ontario were from neoplasms. Of these, 93% occurred within the 45+ years age groups.

EXHIBIT D

NUMBER OF DEATHS IN HAMILTON-WENTWORTH DUE TO NEOPLASM  
BY MAJOR AGE GROUPS: 1979-1982

Age Groups	Deaths 1979-1980	Deaths 1980-1981	Deaths 1981-1982
0-14	8	8	3
15-44	44	49	43
45-64	266	265	296
65-74	181	237	199
75+	193	189	208
Total	692	748	749

Exhibit D shows that the Hamilton-Wentworth experience parallels that of the province with most deaths due to neoplasms occurring in the 45+ age groups.

EXHIBIT E

NUMBER OF DEATHS IN HAMILTON-WENTWORTH DUE TO NEOPLASM  
BY HAMILTON HOSPITALS: 1979-1982

Hamilton Hospitals	Deaths 1979-1980	Deaths 1980-1981	Deaths 1981-1982
McMaster University Medical Centre	55	83	115
Chedoke Hospital	27	33	27
Hamilton General	100	100	99
Henderson General	329	351	334
St. Joseph's	181	181	174
Total	692	748	749

Exhibit E demonstrates that approximately 45% of deaths from neoplasm occur at the Henderson General and 25% occur at St. Joseph's. It also shows that the number of deaths from neoplasm has doubled at McMaster University Medical Centre from 1979-1982 while it has remained stable in the other institutions.



EXHIBIT F

NUMBER OF DEATHS OF HOME CARE PATIENTS BY TOTAL AND  
PALLIATIVE CARE DESIGNATION: 1980-1983

Deaths by Year	Total	Palliative Care-Home Deaths	Palliative Care- Hospital Deaths*
1980-1981	183	24	21
1981-1982	181	71	68
1982-1983	212	74	50

\* Death occurred within 48 hours of hospitalization

Exhibit F demonstrates the trend toward caring for increased numbers of terminal patients in their homes.



OPERATIONAL PLAN FOR REGIONAL PROGRAMME

An operational plan for the Regional Programme would be based on the prioritization of perceived needs and gaps in palliative care in the region. It would be a staged programme with development occurring in all three of the traditional divisions of health care simultaneously. The Programme would need to address the following issues as prioritized:

PATIENT & FAMILY SERVICES

1. Improved communication between individuals/institutions/agencies involved in p.c. and improved continuity of care by:
  - a) development of communication aids:
    - (i) regional travelling record for the patient
    - (ii) p.c. communication record (multicopy) including assessment & interventions
    - (iii) regional pain assessment & evaluation forms
    - (iv) regional medication charting sheet for home patients
  - b) more active involvement by family physicians & the Cancer Clinic
2. Establishment of a case manager for each patient.
3. Improved coordination of services for p.c. patients including:
  - a) a regional definition
  - b) regional standards
  - c) a directory of services available for p.c. patients
  - d) coordination of volunteers regionally
  - e) availability of a 24 hr/day telephone resource for patients & families
  - f) availability of consultation housecalls with family physician
  - g) organized ambulance system to return patients to their primary health care facility

EDUCATION

1. Education of health professionals in all settings re philosophy and concepts of p.c., dying, death & grief processes & resources available to p.c. patients by:
  - a) establishing educational needs within region and coordinating educational programmes to meet the needs
  - b) working with undergraduate, and postgraduate, continuing education programmes to increase the amount of p.c. philosophy & methodology taught in their curricula
  - c) organization of professional training opportunities in p.c., eg., student rotations, placements for family practitioners.
2. Developing and coordinating education programmes for the general public, including patients & families.
3. Developing & coordinating p.c. education programmes for p.c. volunteers.

RESEARCH

1. Development of standardized tools to facilitate audit of existing p.c. services.
2. Study of the effectiveness of the delivery of terminal care based on established indices of good p.c.
3. Comprehensive cost-effectiveness study of p.c. services in the region
4. Evaluation of the effectiveness of the units established in Phase I

PATIENT & FAMILY SERVICES

EDUCATION

RESEARCH

4. Development & Coordination of a bereavement follow-up programme for identified high risk individuals or families (service & education)

5. Increased support for caregivers in family -- financial, physical, emotional -- including:

- a) need for private insurance coverage to extend beyond R.N. to R.N.A. and Homemaker
- b) funding for nursing care & homemaking services in the home when there are no insurance or Cancer Society hours - including patients with non-malignant diseases
- c) funding for equipment, drugs & supplies when not covered by Home Care, Cancer Society or insurances
- d) coverage for patients out of hospital on day passes who need nursing service at home
- e) improved transportation services for patients going for assessment or palliative treatment including ambulance service and need for drivers

"THE PROGRAMMATIC APPROACH"

Definition of the Programmatic Approach

The programmatic approach to health services is area-wide planning and organization of health facilities and services into an effective, efficient and economical system to provide comprehensive programmes of health care, covering the entire spectrum of care, and available to all on an area-wide basis.

It is reorganization of health services from an institutional basis to a programmatic base which assures the best use of limited resources in providing comprehensive health care.

Definition of a Programme

In an attempt to establish more clearly defined guidelines for programme development, the Health Services Committee have produced and received Council approval on the definition of a programme as follows:

1) A District Programme is:-

a system of health care delivery planned and coordinated in such a way as to ensure the best possible use of all resources available within a district or region in order to achieve the highest standard of patient care, medical and para-medical education, and research.

These resources include:-

Manpower (physician, scientist, nurse, technologist, etc.)

Allocated health dollar (capital, operating, building)

Existing buildings, instruments, furnishings, etc.

2) A District Programme may:-

- a) be confined to a particular medical specialty or subspecialty, eg., Programmes in obstetrics, radiology, psychiatry, etc., which may involve a number of subspecialties (abdominal surgery, orthopaedic surgery, E.N.T. surgery and plastic surgery).
- b) involve more than one major specialty or their subspecialties, eg., Programmes in neurosciences involving neurosurgery (subspecialty of surgery), pharmacology, neurology (subspecialties of internal medicine), radiology, psychiatry, etc.  
Organ transplant involving internal medicine, surgery, tissue typing (laboratory medicine), etc.

3. A District Programme may be:-

- a) Regionalized - available in a restricted number of institutions so as to properly utilize costly equipment (without duplication), highly specialized medical and nursing teams, etc., and avoid the very low usage that would result if the programme were offered generally.  
Examples of such programmes would be:-
  - (i) organ transplant where as large a number of cases as possible can then be achieved and where highly specialized teams are required.
  - (ii) radiotherapy - cost of duplicating equipment, especially shielded buildings and rooms, etc.
- b) A Network - available in every institution in its entirety or up to a particular level of sophistication.  
i.e., laboratory medicine, diagnostic radiology, internal medicine, (but not necessarily all its subspecialties) etc. Cardiology would be in this network group as a subspecialty of internal medicine with its own programme.
- c) Mixed - be a network up to a certain degree of sophistication, but with one or more regionalized (highly specialized) facilities, i.e., a cardiology network programme with regionalized cardiac catheterization.



4) A Programme may:-

be restricted to an age group (paediatrics, geriatrics) or a disease (oncology, burns, poisoning, etc.).

5) A Programme may:-

involve other programmes, eg., a programme in paediatrics involves burns, poisoning, oncology, cardiology, neurosciences, etc., a burns programme involves internal medicine, plastic surgery, etc.

From the above it is evident that programmes cannot work in isolation, but must be coordinated with other programmes. The sick child must have ready access to other programmes involved in the paediatric programme (see above). A problem might arise in the case of a patient requiring simultaneously the facilities of two or more regionalized but physically remote programmes, but surely such cases will be rare and it is doubtful if the ideal could be achieved even in one single enormous institution. However, the fewer the institutions the better.

From: Hamilton District Health Council, A Look at the Programmatic Approach to Health Care Delivery in the Hamilton District, 1974.







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